Health promoting factors
in people with chronic musculoskeletal pain
or with rheumatic diseases:
a descriptive and interventional study

Susann Arvidsson
To my family

“Learning is the discovery that something is possible”

Fritz Perls
Abstract

**Aim:** The overall aim of this thesis with a salutogenic approach was to describe health promoting factors in people with chronic musculoskeletal pain and in people with rheumatic diseases, and to evaluate the effects of an intervention study with a self-care promoting PBL-program for people with rheumatic diseases having chronic musculoskeletal pain, sleep disturbances and/or fatigue.

**Methods:** This thesis is comprised of four samples: a randomly selected sample from a Swedish general population (study I) and three different samples containing people with rheumatic diseases registered at a hospital for rheumatic diseases in the southwest of Sweden (studies II, III and IV). **Study I** had a longitudinal cohort design with an eight-year follow-up in a general population. There were 1109 participants without chronic pain and 700 participants with chronic musculoskeletal pain. **Study II** had a longitudinal cohort design with participants with rheumatic diseases (n=185) 12 months after rehabilitation at a hospital for rheumatic diseases. **Study III** had a descriptive qualitative design with a phenomenological approach based on a reflective life-world perspective. Twelve participants were interviewed about their experiences about health-promoting self-care. **Study IV** had a randomised controlled design with post-test six months after the one-year self-care promoting problem-based learning (PBL) program for people with rheumatic diseases. The participants were randomly assigned to the experimental group, 54 participants, or to the control group, 148 participants. Data in studies I, II and IV were analysed with statistics. In study III a Husserlian phenomenological approach based on a reflective life-world perspective was used in the data collection and analysis.

**Results:** **Study I:** Although participants without chronic musculoskeletal pain reported better health-related quality of life (HRQL) than participants with chronic musculoskeletal pain, similar health factors were found to promote a better HRQL in the eight-year follow-up. The most important factors were feeling rested after sleep and having good sleep structure. **Study II:** The most important factors promoting better outcome in HRQL 12 months after rehabilitation in participants with rheumatic diseases were
having a strong sense of coherence (SOC), feeling rested after sleep, having work capacity, and having good sleep structure. *Study III:* The meaning of health-promoting self-care as experienced by people with rheumatic diseases was that self-care takes place against a background of continual hope and belief to be able to influence health in positive ways. Self-care was a way of life and implied being ready to understand and respond to signals from the body. Three interrelated constituents elucidated the experiences: dialogue, power struggle and choice. *Study IV:* At the six month follow-up the participants in the experimental group had stronger empowerment after participation in the self-care promoting PBL-program compared with the control group which only got standard care for people with rheumatic diseases. There were no differences in HRQL, self-care ability, SOC, pain, quality of sleep or fatigue between the experimental group and the control group. The participants in the experimental group also stated that they had implemented lifestyle changes which they had not done without the PBL-program.

**Conclusion:** The results of this thesis provide a valuable and useful insight in health promoting factors in people with chronic musculoskeletal pain and in people with rheumatic diseases, but also in that people with rheumatic diseases have benefit from taking part in patient education with a self-care promoting PBL-program. These results contribute to evidence supporting the introduction of a more salutogenic approach in rheumatology care and research.
Original studies

This thesis is based on the following studies, which are referred to by their Roman numerals in the text:

**Study I**
Arvidsson S, Arvidsson B, Fridlund B, Bergman S.
*Health predicting factors in a general population over an eight-year period in subjects with and without chronic musculoskeletal pain.*
Health and Quality of Life Outcomes 2008;6:98.

**Study II**
Arvidsson S, Arvidsson B, Fridlund B, Bergman S.
*Factors promoting health-related quality of life in people with rheumatic diseases: a 12 month longitudinal study.*
BMC Musculoskeletal Disorders. Accepted.

**Study III**
Arvidsson S, Bergman S, Arvidsson B, Fridlund B, Bengtsson Tops A.
*Experiences of health-promoting self-care in people living with rheumatic diseases.*

**Study IV**
Arvidsson S, Bergman S, Arvidsson B, Fridlund B, Tingström P.
*Effects of a self-care promoting problem-based learning program as reported by people with rheumatic diseases: a randomized controlled pilot study.*

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Studies I-IV
Abbreviations

ASA-A The Appraisal of Self-Care Agency Scale
CI Confidence interval
EU European Union
GRR General resistance resources
HRQL Health-related quality of life
IASP International Association for the Study of Pain
OR Odds ratio
PBL Problem-based learning
RA Rheumatoid arthritis
SF-36 Short Form-36 Health Survey
PF Physical Functioning
RP Role-Physical
BP Bodily Pain
GH General Health
VT Vitality
SF Social Functioning
RE Role-Emotional
MH Mental Health
SLE Systemic lupus erythematosus
SNASS The Social Network and Social Support Scale
SOC Sense of coherence
SWE-RES-23 The Swedish Rheumatic Disease Empowerment Scale
VVV Våga-vilja-veta
WHO World Health Organisation
Introduction

Chronic musculoskeletal pain and rheumatic diseases are major public health problems in the world. These diseases can cause great suffering and disability but also a great social and economic burden on the individuals and their families [1]. It has also been shown that people with these diseases estimate HRQL as low [2-4]. In order to early identify and reduce the negative impact on HRQL from musculoskeletal disorders, there is a need for more knowledge regarding factors associated to a positive impact on HRQL. In studies the priority has primarily been on risk factors (pathogenesis) instead of individuals’ own capacity to adopt factors that promote their health (salutogenesis) [5, 6]. The goal of a salutogenic approach is to strengthen an individual’s resources to be more resistant to debilitating impact [7].

People with RA express a great need for education, support and assistance in adapting to the disease [8] and the individual can get this within patient education but also a kind of power to provide an opportunity to actively participate in different decisions regarding their own health [9]. Patient education must be based on the individual's educational needs [10, 11] and this requires a conscious pedagogical approach for more extensive learning activities, as teaching something is not the same as learning something [10]. However, prevailing patient education has not revealed any evidence of long term benefits [12].
Background

Chronic musculoskeletal pain
Pain is a common symptom in disorders of the musculoskeletal system. The established definition of pain, according to IASP, is: “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” [13]. This means that pain is a subjective experience and unquestionable. Pain is always unpleasant and therefore also an emotional experience that affects each individual in a unique way [14]. Chronic pain is in turn defined by IASP as “pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be 3 months)” [15] (p. 1). In Europe chronic musculoskeletal pain of moderate or severe intensity occurs in 19% of the adults [16] and in Sweden in 34.5% to 46% [17, 18]. Chronic musculoskeletal pain is an interaction between biological and psychological processes [19]. Lifestyle, psychosocial and environmental factors affect the strength and extent of the chronic musculoskeletal pain [19, 20].

Rheumatic diseases
The burden of chronic musculoskeletal pain in rheumatic diseases is a very common finding [21]. In the world there are over 150 registered rheumatic diseases [22], but the concept of rheumatic diseases still has no clear definition in the absence of solid aetiological evidence for most of the diseases [23]. Internationally the prevalence of rheumatic diseases in people older than 65 years of age is between 41-53% [24]. Nearly a ninth of the adult population in Sweden [25] and nearly a quarter of the adult population in Greece [26] as well as in Israel [27] are affected by rheumatic diseases.

The rheumatic diseases are usually divided into four main groups: inflammatory joint diseases, systemic rheumatic diseases, osteoarthritis and spondylosis, and local and generalised pain [28]. Rheumatic diseases have a great variation in terms of severity and complexity [22]. Many of the rheumatic diseases relate to each other and have overlapping symptoms. The aetiology is often unknown but various factors such as infections, stress and trauma could be a trigger in people with a genetic disposition [1, 28]. The rheumatic diseases differ in causes and courses but most of the rheumatic diseases affect the musculoskeletal system (bones, joints, soft tissues and
muscles) with symptoms like pain and stiffness. There are also large individual differences in the severity of the same rheumatic disease for different individuals [1, 25]. The treatment may thus differ greatly from individual to individual, but the most common treatment modalities regardless of diagnosis are drug therapy and exercise. The objective of this treatment is to reduce or alleviate symptoms, suppress disease activity and reduce the appearance of skeletal changes [1, 29]. Rheumatic diseases and their treatments could have a significant adverse impact on the individual from physical, mental and social aspects [1, 30] and it can also affect their family and friends [31]. It means that each individual must be treated as an individual with his or her own plan of health care [1]. People with RA regard outcomes such as staying independent, having less pain, keeping mobile, returning to or maintaining a normal lifestyle, feeling well and feeling less fatigued as more important than traditional disease activity outcomes such joint swelling and stiffness [32, 33].

Health and a salutogenic model

WHO has stated that it is a basic human right to enjoy health regardless of sex, age, ethnicity, diseases and so on [34]. Health is a concept which is often discussed but the most frequently used definition of health from 1948 and made by WHO still is, “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [35]. This means that people who have the opportunity to experience health have a resource in daily life [34]. Another definition of health is that “health is a condition that concerns the whole man and is an experience of being in balance. This involves both a sense of inner balance and a sense of balance in relation to fellows and to life itself” [36] (p. 49, the English translation is made by the author of this thesis). This definition is similar to the ideas about the salutogenic model which Antonovsky (1923-1994), a professor of medical sociology, described in 1979 [37]. Antonovsky was critical to the pathogenic model (risk factors’ impact on health) but did not want to replace it with a salutogenic model (factors promoting health). He wanted the two models to be complementary to each other [5, 7]. Antonovsky said, ”If, then, we can begin to understand this mystery – the mystery of survival, the mystery of why some people’s is such that they go through life for some of the time with relatively little pain and suffering – we might begin to think
about applying this understanding to reduce pain and suffering among the rest of us” [37] (p. 36).

According to Antonovsky the pathogenic model dichotomises between being sick or not and there are no intermediate steps. However, the salutogenic model is a multidimensional continuum between well-being (health) and the absence of well-being (illness). Where the individual is between these poles is dependent on what happens in his or her life [37]. Salutogenic means an understanding that the individual has more or less health while the individual has more or less illness. The goal of a salutogenic model is to strengthen the individual’s resources to be more resistant to debilitating impact. The whole individual with all of his or her experiences and all of the socio-cultural systems in which the individual lives is included in the analysis of the individual’s resources to solve problems [7].

The theory of sense of coherence
The theory of sense of coherence was developed by Antonovsky and the starting point was the salutogenetic model [5]. According to this theory there are two key concepts: GRR and SOC. The GRR are biological, material and psychosocial factors like money, knowledge, experiences, healthy behaviour, social support and traditions, which make people’s lives easier. If the individual has some of these GRR there is a better chance for the individual to deal with challenges in life. However, the ability to use the GRR, determined by the level of SOC, is more important than the GRR themselves [5, 38, 39]. The core of this theory is thus the SOC and its influence on the individual’s experience of stress and how to deal with stressful situations. The main function of SOC in stressful situations is to prevent the conversion from tension to stress [5, 38]. Antonovsky summarizes the SOC, “Sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring, though dynamic, feeling of confidence that (1) the stimuli deriving from one’s internal and external environment in the course of living are structured, predictable and explicable; (2) resources are available to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement” [5] (p. 46).

The SOC is covered by three concepts: comprehensibility, manageability and meaningfulness. Comprehensibility is the cognitive component. This concept describes if you are experiencing both internal and
external stimuli as understandable, clear, coherent and structured. **Manageability** is the controlling component which means the degree to which an individual experiences that he or she can handle a situation and choose resources which are available for use to meet the requirements of the situation. **Meaningfulness** is the motivational component. Antonovsky viewed the meaningfulness as the key component. It describes to what degree the individual feels life to be of emotional importance. No matter what happens the individual tries to see a sense of what is happening and see if it is a challenge which is worth investing energy and commitment in [5].

If an individual experiences life as understandable and manageable while finding a purpose in dealing with problems that arise, then this individual has a greater ability to stay healthy. The most important determinant for SOC is personal relationships and not the social environment. According to Antonovsky the SOC changes very little in adulthood (after age 30) once it is created, at least in a positive direction [5], but later evidence shows that SOC tends to increase with age throughout life [40, 41]. Some major life changes can affect the SOC, such as if the individual emigrates, moving to another place, the birth of a child, getting another job, going into psychotherapy, etc. Of great importance when developing a strong SOC is that the individual has a balance between demands and resources [5]. The level of SOC is strongly correlated to the perceived level of health, especially mental health, regardless of the age, gender and nationality [42].

In people with RA a strong SOC is associated with better clinical status (like global health and pain) [43] and with a higher physical HRQL, but the relationship is mediated by psychological distress [44]. It has been shown that people with RA who have stronger SOC have less incidence of depression [45] and women with fibromyalgia who have a stronger SOC perceive greater well-being as well as feel more hopeful, free, valuable and more like others [46]. It has also been shown that individuals with fibromyalgia who have stronger SOC report better health than individuals with matching diseases who have weaker SOC [47]. Individuals with SLE who have strong SOC have the ability to predict, explain and cope with disease related stressors and achieve a better HRQL [48]. However, the SOC alone does not influence health and a person with a strong SOC does not necessarily always have a healthy lifestyle [5, 42]. It has also been found that
the SOC is not as stable as Antonovsky assumed. More studies are needed to determine whether a stronger SOC is a cause of health or if health causes a stronger SOC [40, 49].

Health promoting factors
Better health is central to people’s well-being and many factors can influence their health status [50]. Factors influencing the health status can be risk factors but also health promoting factors. There are many definitions of the concept risk factors, but none has been found on the concept health factors or health promoting factors. This is perhaps reflecting the paradigm in which the overwhelming research has been made [5, 6]. However, EU states that the most important health factors are people’s social and economic conditions with a close connection with living and working conditions. Other important factors that affect the health are diet, exercise and how people treat themselves and others [51]. Health factors can also be described by Antonovsky’s description of the GRR, i.e. the potential resources (inner and external) which are available to the individual and which can facilitate health promoting activities [5, 38, 39].

Health-related quality of life
HRQL is often investigated when the health development will be studied in populations with chronic musculoskeletal pain or rheumatic diseases. The concept HRQL, however, has no general definition, but it has been determined that HRQL is one dimension of the wider concept quality of life [52]. The WHO defined quality of life as “individual’s perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment” [34] (p. 17). This definition is embedded in a cultural, social and environmental context [34]. Within research the interest has been focused on how peoples’ lives are affected by their diseases and treatments. To mark this distinction they often use the term HRQL but this does not give any limitation on the multidimensional view of the quality of life [53, 54]. According to Tengland HRQL has “two central meanings: health-related well-being, which
constitutes quality of life, and health as ability, which contributes causally to quality of life” [55] (p. 155).

It has been shown that people with musculoskeletal pain estimate their HRQL as very low compared to a pain free population and that the perceived low health can predict musculoskeletal pain outcome [2, 56, 57]. It is also a common factor for people with rheumatic diseases such as fibromyalgia [4, 58, 59], SLE [60-62], primary systemic vasculitis [63-65], systemic sclerosis [3, 66, 67] and RA [68-70] to estimate the HRQL as low. The low HRQL is due to that the rheumatic diseases provide a considerable disease burden [1, 71]. The physical impact is dominant in RA, but the disease also provides psychological and social consequences [69]. Pain, fatigue [1, 72, 73] and sleep disturbances are some of the most important deterioration factors on the HRQL for people with RA [1, 72].

Empowerment

Empowerment is a concept which is closely related to health and HRQL [74, 75]. WHO has determined that there is evidence that empowering initiatives lead to positive health outcomes and that empowerment is a very important public health strategy [76]. The concept empowerment is defined by WHO as “a process through which people gain greater control over decisions and actions affecting their health” [34] (p. 6). Empowerment can be likened to a journey; it is created as we work our way through it. Thereby, empowerment is created in relation to other individuals; it is a multidimensional social process [74, 75, 77]. Empowerment could also be seen as a complex goal to have control over the determinants of one’s HRQL [74, 75].

The fundamental base of empowerment is to meet the individual’s needs. An empowerment approach involves helping the individuals to learn to think critically and to make informed decisions [78]. However, traditional information given to individuals by health-care professionals is not empowerment, but individuals cannot be empowered without information [79]. Within patient education where nurses share their professional knowledge, it can give the individual a kind of power and provide an opportunity to actively participate in different decisions regarding a person’s own health [9]. The health-care professionals are responsible for helping the individuals and to ensure that the individuals have the knowledge and resources to make thoughtful decisions. The individual is then responsible
for the consequences of his or her decisions about self-care. The empowerment approach involves facilitating and supporting individuals to reflect their experiences. Self-reflection could lead to enhanced awareness and understanding of the consequences of their decisions about self-care [78]. An individual who has empowerment has the knowledge, skills, attitudes and awareness needed to be able to influence his or her own health through behavior [80]. Individuals with RA describe that they control their health problems with positive thinking and perseverance but also through the support of the family and the good relationship with health-care professionals [81].

Self-care and self-care activity
In order for people with chronic musculoskeletal pain or rheumatic diseases to achieve health and empowerment, self-care activity is one opportunity [78, 80, 82]. Self-care is a concept which has been defined by WHO as "activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals" [83] (p. 2). A similar definition has been made by Orem (1914-2007), a nursing theorist in the area of self-care. She defined self-care as a “practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being” [84] (p. 43). According to these definitions, self-care is a process. This process consists of actions of investigating, formulating and expressing requirements, but also making judgements about what should be done. When individuals perform actions it requires essential power which is activated through stimuli [84, 85]. It has been shown that adults have ability to act towards maintaining health and to treat themselves in the event of illness or injury [84]. These abilities are learned through relationships and communication with other people and are conscious acts [84, 85].

In people with rheumatic diseases, self-care is a multi-dimensional and complex process where the purpose is to bring about order in their lives. The process involves recognising and monitoring boundaries of the body, mobilising resources, managing the shift in self-identity as well as balancing,
planning and prioritising in life [86]. The way in which individuals perform self-care is dependent on how responsibility is attributed. If the individual attribute external responsibility they state that they have no influence over the disease. The health-care professionals are assigned the responsibility. When the responsibility is attributed to internal factors is the individual active in his or her own care and is taken responsibility for himself or herself. They also use more multifaceted self-care activities [87]. It has been found that people with rheumatic diseases use several self-care activities in their efforts to mitigate the diseases, maintain independence and prevent loss of valued life activities [88, 89]. Such self-care activities are, for example, adopting an acceptance of the disease, trying to have a positive attitude, exercising regularly, using alternative treatment methods, and using distractions in activities that stimulate and maintain independence [89]. When people with RA feel control of their disease, they are more independent and more satisfied with their health [90, 91]. People with rheumatic diseases learn how to respond to symptoms and consequences of the diseases by reflecting over the outcomes of successful or unsuccessful self-care activities [86]. The most important factor for better self-care behaviour is to give people the knowledge to understand why they need to do the self-care. Health-care professionals but also family and friends are important sources of information, guidance and support for self-care [82]. Thus, personal and social resources are important when trying to tolerate and manage the burden of the disease [92].

**Patient education**

Patient education is one approach that health-care professionals often use when they are supporting individuals in self-care activity. During the last decades patient education has been developed as an integral part of patient care, but there is no uniform definition of the concept in the world even if it is used very frequently. Patient education, patient teaching and patient information have sometimes been used synonymously. Each of these concepts implies a focus on knowledge [10]. Patient education can be defined as “planned, organized learning experiences designed to facilitate voluntary adoption of behaviours or belief conducive to health. It is a set of planned educational activities that are separate from clinical patient care. The activities of a patient education program must be designed to attain
goals that the patient has participated in formulating” [93] (p. 2). This means that the purpose of patient education is that individuals must participate actively in their care and get knowledge and skills to manage their self-care in the best way. The individuals need knowledge about how to carry out treatment recommendations, but knowledge alone is not always a predictor of behavioural changes [10]. The individuals’ self-knowledge, pre-understanding and experience of their disease have a significant impact on how the self-care may be affected by the patient education, if they take more responsibility for the health and the results that can be achieved. Essential for the results are also to give the individual an opportunity to have dialogues with health-care professionals like nurses, to reflect on the knowledge [1, 94, 95].

It is important to improve the individuals’ ability to reach decisions and make more independent choices in relation to diseases and illnesses [94]. Both experienced and recently diagnosed individuals with RA express information and support needs which are underpinned by involvement and choice [96]. Rheumatology nurses have an important role in educating individuals with RA to cope with the disease and to increase the personal control over the disease [97]. Hill states that “the essence of rheumatology nursing is the ‘Three E’s’; educating, empowering and enabling” [1] (p. xv) people with rheumatic diseases. However, it has been shown that rheumatology nurses give much information about drugs and blood tests but little about self-care to the individuals with RA [98]. It has also been shown that people with RA want to be informed and that they express a great need for information about the disease and its treatments [99], but they do not always understand the information and have the confidence to ask for clarification [100]. The use of pedagogical models in patient education in rheumatology care is deficient. Mäkeläinen et al. states that it is important to develop new pedagogical methods in patient education to encourage the participants with rheumatic diseases to be independent and give them the ability to influence their own health [98]. However, maximum of effectiveness of the patient education will only be reached if it is presented to the right individual at the right time in an appropriate format. It means that a variety of strategies have to be employed at different stages of an individual’s illness [101].
The average quality of studies about patient education interventions in people with RA is not very high and they have small short-term effects on disability, the individual’s global assessment, psychological status and depression. There is no evidence of long term benefits of the patient education [12]. It has also been shown that there are methodological limitations in patient education interventions in rheumatology care, such as insufficient relevant outcomes and lack of consensus for outcomes [102].

Problem-based learning
One strategy in patient education is group teaching which has been shown to be a great way of teaching the ability to problem solve and self-care [101]. PBL is a pedagogical model for group teaching and was developed by Barrows and Tamblyn in the 1950s and the 1960s [103, 104]. Barrows and Tamblyn defined PBL “as the learning that results from the process of working toward the understanding or resolution of a problem” [105] (p. 18).

In the early literature the theoretical underpinnings of PBL are not well expressed. Rideout states that “the model appears to have arisen from the personal experiences and beliefs of a few medical educations and can perhaps be said to have had nontheoretical beginnings” [106] (p. 24-25). Some researchers argue that information-processing theory underlies PBL [104, 107] but also theories like cooperative learning, self-determination theory and control theory [107]. Silén has found that the theoretical starting points for PBL can be pragmatism, adult educational research, cognitive psychology, research on meaningful learning and social constructivism [108, 109].

The basic ideas behind PBL are that the individuals have to investigate an approach to learning, take self-responsibility for learning, find functional knowledge, think critically, and find a way to lifelong learning and self-evolution. The learning is based on relevant real-situations to desired learning outcomes, which are analysed and discussed [106, 109]. The purpose of using problems in PBL is to stimulate the learning of information and concepts but also to teach a method of approaching and an attitude towards problem solving [110]. Important components of PBL are cumulative learning, integrated learning, progression and consistency in learning. PBL is not static learning [111].
There are three processes in PBL: the problem-solving process, the group process and the learning process. Processing problems means to see the problem, analyse and examine it, determine what is most important, find and apply the explanations or solutions, and assess the impact of various applications. The work in the group becomes a platform to develop an investigative approach. A prerequisite for progress towards a well functioning group is that the group members are given the opportunity to train to receive and give feedback. The pre-understanding each one has needs to be challenged by others' opinions and insights to be clear for the individual and group. Learning is an active process and is unique to each individual [109, 111]. Previous learning is acknowledged and the present experience will build on it. Self-evaluation, critical thinking and reflection are important parts of PBL and also a feature of lifelong learning. Individuals’ motivations to learn are enhanced when their learning is evaluated and they receive credit for their work [106]. Motivation is a force which triggers the learning process [109].

A problem-based tutor’s role is to use his or her expertise to guide and assist the individuals in the discussion and decision making. A tutor must learn to trust the individuals to do the work of learning [106, 111]. The tutor’s skill is important for the results of the individual’s learning [112], but it is important to know that the tutor does not have all the answers [111].

**Problem-based learning in patient education**

PBL is associated with self-directed and the retaining of knowledge, critical thinking or problem solving, managing uncertainty and communication learning while these skills are also needed by individuals with a chronic disease in order to manage their condition. Therefore, PBL can be a way of combining education, counselling and behaviour intervention to support individuals with a chronic disease to perform self-care. PBL can help individuals to activate prior knowledge and connect new knowledge to prior knowledge. Individuals who participate in discussions can be able to adjust and manage various scenarios that can be associated to their chronic disease [113].

PBL in patient education has been proven to be a useful method to provide the individuals increased knowledge and motivation that will affect their own behaviour towards better health [114]. Individuals with RA state
that they have it easier in managing pain and other problems with the rheumatic disease after the problem-based education program [115]. Women with fibromyalgia or with other non-malignant pain state that they have strengthened their internal resources such as self-confidence and ability to act in a social setting after participation in a problem-based rehabilitation [116]. Studies with people with other chronic diseases show similar results like individuals with asthma who participated in a problem-based educational program on health. They describe that their self-confidence increased, that they had begun to reflect on themselves and the disease, and begun to use new strategies to cope with the disease [117]. People with diabetes who participated in a patient education program with PBL state that they take a more active role in the medical consultation. Their awareness has grown from the importance of managing the treatment of the disease as well as their helplessness and anxiety has decreased. The belief in their own ability has increased, but also the ability to motivate themselves towards various activities [118]. Experiences of a PBL program for people with blindness caused by diabetes were increased self-efficacy and knowledge. PBL was experienced as a flexible learning method and the content was given stimulation and creativity [119]. Individuals with coronary artery disease report after a PBL education program that they have implemented lifestyle changes [120]. Williams and Pace settled that although studies using PBL as an intervention with chronic disease self-management reflect significant changes, more research is required to confirm the efficacy of using PBL in patient education [113].
Rationale for the study

The literature shows that chronic musculoskeletal pain and rheumatic diseases are major public health problems. These diseases cause great suffering and disability but also a great social burden to the individuals. It has also been shown that individuals with these diseases estimate their HRQL as low, but individuals with RA who have strong SOC estimate higher HRQL than individuals with RA who have lower SOC. People with rheumatic diseases use several self-care activities in their efforts to mitigate the diseases, maintain independence and prevent loss of valued life activities and health. However, the individuals need knowledge about how to carry out the disease and treatment recommendations. Even so, knowledge alone is not always a predictor of behaviour changes. The individuals also need empowerment to gain control over decisions and actions affecting their health. To meet the individuals’ needs of knowledge and empowerment patient education has been developed as an integral part of nursing care, but it is common to provide the patient education to a passive individual.

There is a distinct lack of studies that have studied factors promoting HRQL in people with chronic musculoskeletal pain or rheumatic diseases and how health-care professionals can help these individuals to improve their HRQL with, for instance, patient education. The average quality of studies about patient education interventions in people with RA is not very high and they have small short-term effects. There is no evidence of long term benefits of the patient education. In order to understand and assist individuals to a better HRQL, more research has to focus on factors that could have positive impact on HRQL and not only identify risk factors. More research is also needed to further develop patient education with various pedagogical models that can provide a more long-term impact on the individual’s HRQL.

The importance of this thesis is that by studying the various factors that may promote HRQL in people with chronic musculoskeletal pain and in people with rheumatic diseases new knowledge with evidence from research is obtained which is of importance from both an individual and a clinical perspective. From an educational perspective the importance of this thesis is that the obtained knowledge is used to develop a self-care promoting PBL-
program. This PBL-program is intended to develop and complement the existing rheumatology care, which is important from both an individual and a clinical perspective. Then, if individuals with rheumatic diseases by participating in a PBL-program improve their HRQL and empowerment by learning and adopting self-care activities this is also of importance from a societal perspective.
Overall and specific aims

The overall aim of this thesis with a salutogenic approach was to describe health promoting factors in people with chronic musculoskeletal pain and in people with rheumatic diseases, and to evaluate the effects of an intervention study with a self-care promoting PBL-program for people with rheumatic diseases having chronic musculoskeletal pain, sleep disturbances and/or fatigue.

The specific aims of the different studies were:

- To investigate the associations between suggested health factors and HRQL at baseline and in an eight-year follow-up in people with and without chronic musculoskeletal pain in a cohort from a general population (study I).

- To investigate the associations between suggested health promoting factors at baseline and outcome in HRQL at a 12 month follow-up in people with rheumatic diseases (study II).

- To explore and describe the meaning of the phenomenon of health-promoting self-care as experienced by people living with rheumatic diseases (study III).

- To evaluate the effects of a self-care promoting PBL-program for people with rheumatic diseases in terms of HRQL, empowerment and self-care ability at a six month follow-up (study IV).
Materials and methods

Ontological and epistemological framework

This thesis had the ontological perspective of nursing science, to see people as a whole (holism) and that they were in the world with others, as a starting point [121]. This perspective was well in line with the salutogenic model which was used as a basis. The salutogenic approach in this thesis means that the focus was on factors and conditions that help people to maintain their health and social functions even if they were exposed to both external and internal pressures. The salutogenic model looks beyond the idea that the individual was either healthy or sick. The adoption of the salutogenic model is autonomy and holism. Autonomy means that the individual is independent and has self-determination [5]. This naturalistic paradigm is associated with an inductive reasoning and qualitative research. However, the nursing research has been dominated for decades by the positivistic paradigm. In a positivistic paradigm the researchers try to understand the underlying causes of natural phenomena and seek the objective reality and generalisations. Deductive reasoning and quantitative research is associated with the positivistic tradition [122]. According to Polit et al. the uses of multiple paradigms are “lenses that help to sharpen our focus on phenomena of interest, not blinders that limit intellectual curiosity. […] Nursing knowledge would be meagre without a rich array of methods available within the two paradigms – methods that are often complementary in their strengths and limitations” [122] (p. 18). In this thesis the four studies had been anchored in both a positivistic approach (studies I, II and IV) and a holistic approach (study III) to answer the overall aim. In studies I and II the researchers investigated suggested factors and tried to understand their effect on the participants’ health (ontology). The researchers were independent and objective towards the participants. Epistemologically it was a deductive process which was based on a theory with a system of testable hypotheses. In the randomised controlled study (study IV) the researchers tested some of the results that had been shown in studies I, II and III [122]. The ontological reality in a holistic approach means striving for an in-depth understanding of the human. Study III had a phenomenological approach based on a reflective life-world perspective and moved between the whole – the parts – the whole and tried to capture its meanings and essence. Epistemologically it was an
inductive process which was based on data from the individuals lived experiences of the phenomenon and which lead to the formulation of the essence. The researchers in study III were interacting with the individuals through the interviews and the results were created in these interactive processes. The studied phenomenon is not being described objectively, but rather it is the individual’s experiences of the phenomenon [123]. The two approaches, the positivistic and the naturalistic, in this thesis should not be seen as dichotomies but guidelines for the research designs, as well as for the choices of data collections and analysis. Both a positivistic approach and a naturalistic approach are essential to health-care professionals in order to help people to strengthen their health, to alleviate the suffering of diseases or illness and to mitigate the consequences this may give them [36].
Study designs

In order to respond to the aims of the thesis, the following four designs were used:

- A longitudinal cohort design with an eight-year follow-up including participants with and without chronic musculoskeletal pain in a Swedish general population (study I).

- A longitudinal cohort design including participants with rheumatic diseases 12 months after rehabilitation at a hospital for rheumatic diseases (study II).

- A descriptive qualitative design with a phenomenological approach based on a reflective life-world perspective including participants with rheumatic diseases (study III).

- A randomised controlled design with a one-week and a six month follow-up after a one-year self-care promoting PBL-program for people with rheumatic diseases who had chronic musculoskeletal pain, sleep disturbances and/or fatigue (study IV).

An overview of the relationship between the studies is presented in figure 1.
Figure 1 Overview of the studies and their relationship in the thesis.

**Sample and criteria**
This thesis is comprised of four samples: a randomly selected sample from a Swedish general population (study I) and three different samples containing people with rheumatic diseases registered at a hospital for rheumatic diseases in the southwest of Sweden (studies II, III and IV). An overview of the studies’ design, participants, data collection, instruments and analysis is presented in table 1.
## Table 1: Overview of the studies’ design, the participants and their sex and age, data collection, instruments and analysis

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Longitudinal Cohort</td>
<td>Longitudinal Cohort</td>
<td>Descriptive Controlled</td>
<td>Randomised Controlled</td>
</tr>
<tr>
<td>Participants</td>
<td>1 809 with or without chronic musculoskeletal pain</td>
<td>185 with rheumatic diseases</td>
<td>12 with rheumatic diseases</td>
<td>162 with rheumatic diseases</td>
</tr>
<tr>
<td>Sex</td>
<td>Men</td>
<td>With pain: 271 (39%)</td>
<td>46 (25%)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Without pain: 531 (48%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>With pain: 429 (61%)</td>
<td>139 (75%)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Without pain: 578 (52%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, mean (min-max)</td>
<td>With pain: 44.6 (20-74 years)</td>
<td>59.4 (18-88 years)</td>
<td>48.6 (37-73 years)</td>
<td>Experimental group: 56.4 (37-68 years)</td>
</tr>
<tr>
<td></td>
<td>Without pain: 50.3 (20-74 years)</td>
<td></td>
<td></td>
<td>Control group: 55.2 (21-78 years)</td>
</tr>
<tr>
<td>Data collection</td>
<td>Questionnaire at baseline and after eight years</td>
<td>Questionnaire at baseline and after twelve months</td>
<td>Unstructured interview at one occasion</td>
<td>Inclusion questionnaire and a questionnaire at baseline and after one week and six months</td>
</tr>
<tr>
<td>Instruments</td>
<td>SF-36</td>
<td>SF-36 SNASS SOC</td>
<td>ASA-A SF-36 SOC SWE-RES-23</td>
<td></td>
</tr>
<tr>
<td>Analysis</td>
<td>Chi-square test Independent t-test Multivariable logistic regressions</td>
<td>Chi-square test Independent t-test Multivariable logistic regressions</td>
<td>Phenomenological approach based on a reflective life-world perspective</td>
<td>Chi-square test Independent t-test</td>
</tr>
</tbody>
</table>
Study I
In study I the participants were selected from the target population of all 70,704 inhabitants aged 20-74 years in two municipalities on the west coast of Sweden in 1995. In each of the two municipalities every 18th man and woman was selected through the official computerised population register. A sample of 3,928 individuals were representatives for the target population and there were 2,425 individuals accepted to participate in the study. In 2003 there remained 2,332 potential participants and 1,849 participants (79%) still accepted to participate in the study. The 1,849 participants were divided into two groups according to their response about chronic musculoskeletal pain. At baseline there were 1,109 (60%) participants without chronic musculoskeletal pain and 700 (38%) participants with chronic musculoskeletal pain. There were missing data on pain for 40 (2%) participants. There were 578 (52%) women and 531 (48%) men without chronic musculoskeletal pain and their mean age was 45 years. In the group with participants with chronic musculoskeletal pain there were 429 (61%) women and 271 (39%) men and their mean age was 50 years.

Study II
In study II individuals, aged 18 years or older and primarily from the middle and south of Sweden, were referred by physicians to an inpatient rehabilitation program at the hospital for rheumatic diseases. All individuals (n=249) with at least one diagnosed rheumatic disease who received three weeks of rehabilitation during the period February – June in 2007 were asked to participate in the study one week after discharge from the hospital. There were 200 (80%) individuals included one week after rehabilitation and at the 12 month follow-up 185 (74%) individuals fulfilled the study. There were 139 (75%) women and 46 (25%) men, and their mean age was 59 years.

Study III
In study III the individuals were registered at the hospital for rheumatic diseases, had for more than a year at least one diagnosis of rheumatic diseases, and had not been cared for by the researcher. In this sample the variations of experiences were guarantied by strategically selecting with regard to sex, age, rheumatic disease and ethnicity [123]. Thus, 12
individuals were strategically selected from the waiting list for regular visits to the rheumatologists and all asked individuals wanted to participate in the study. Their mean age was 49 years. Two of the participants were born in other countries than Sweden, one from South America and one from Central Europe.

**Study IV**

In study IV the "inclusion-questionnaire" with four questions (whether to participate in the PBL-program, having had musculoskeletal pain, sleep disturbances and fatigue during the last three months) was sent to 800 individuals registered at the hospital for rheumatic diseases. There were 202 individuals who met the inclusion criteria and had for more than a year at least one diagnosis of rheumatic diseases and reported having musculoskeletal pain, sleep disturbances and/or fatigue during the last three months, and wanted to participate in the PBL-program.

After completing a larger pre-test questionnaire they were randomly assigned to the experimental group, 54 participants, or to the control group, 148 participants. There were 51 participants who began the PBL-program and after one year there were 38 participants (75%) who had completed the entire PBL-program. All 38 participants in the experimental group answered the six month post-test. At the post-test one week after the PBL-program completion, there were 131 participants (89%) who remained in the control group and after six months there were 124 participants (84%) (Figure 2).
The one-year intervention

Figure 2 Flow chart of the participants in the intervention pilot study.
At the inclusion to study IV there were 598 individuals who decided not to participate in the study, of whom 225 (38%) were men and 373 (62%) were women. Their ages were between 17-83 years and the mean age was 54.2 (SD 14.3). There were 389 voluntary explanations from the individuals about why they were not attending the study. They were, for instance, the work situation (n=93, 24%), not having any of the inclusion problems (n=89, 23%), residing too far from the hospital and not getting economic compensation (n=54, 14%), having the inclusion problems but not wanting to participate (n=47, 12%), only problems with pain (n=31, 8%) or feeling too weak (n=23, 6%).

**Intervention (study IV)**

Study IV, an intervention pilot study, was carried out over a period of 12 months. The intervention was the PBL-program which was run alongside the usual standard care that all participants in the experimental group and in the control group received at the hospital for rheumatic diseases. The standard care was dependent on, for instance, the participants’ diagnosis and the severity of the disease but also what treatment the participant preferred. At the start of the PBL-program, each individual in the experimental group was allocated to a group of seven or eight participants with rheumatic diseases and one tutor who was a nurse. Each group met for one and one half hours, ten times in a one-year period. They met every other week during two months and then about every other month the rest of the year.

**The curriculum**

A curriculum for the PBL-program was developed together with the tutors. As guidance in preparing the content of the curriculum, results from other studies [114, 120] were used, but also proposals and comments from six other individuals with rheumatic diseases who participated in a focus group interview prior to the PBL-program. The results from studies I and II that improved sleep, less fatigue and pain improve HRQL were also used as guidance in preparing the content of the curriculum. In study II there was also a question, *If you would like to improve your general health, what change would you first have focus on?* The response options were: sleep habits, dietary habits, exercise habits, leisure habits, sexual habits, social
support, stress habits, tobacco habits, snuff habits, alcohol habits and an open alternative where they could write anything they wanted to change. All response options turned out to be important and pain was the most frequently mentioned at the open alternative. Then the results from study III, how health-promoting self-care could be experienced by people with rheumatic disease, were used in the training and mentoring of the tutors. The results from study III also confirmed the results from the previous focus group interview. In the curriculum following starting points were predetermined as linked to self-care for people with rheumatic diseases that were having chronic musculoskeletal pain, sleep disturbances and fatigue: self-awareness and self-confidence, relationships to other, stress and relaxation, physical activity and rest, medicines and herbal remedies, tobacco and alcohol, and food and drink. Each PBL-group could also discuss further areas that they considered important.

The purpose of the PBL-program was that the participants had to investigate an approach to learning, take self-responsibility for learning, find functional knowledge, think critically, and find a way of lifelong learning and self-evaluation. The participants were expected to get an opportunity to find approaches to self-care and to be able to handle the chronic musculoskeletal pain, sleep disturbances and fatigue thereby improving their HRQL and the belief in their own ability.

The name of the PBL-program, the Dare-Want-Know program (in Swedish: Våga-Vilja-Veta program = VVV program), was based on the three processes in PBL: the problem-solving process, the group process and the learning process (see page 22). The participant had to be daring and willing to see, analyse and examine the problem in order to learn more about themselves and their self-care [109, 111].

The self-directed learning
At the first meeting in the PBL-program the focus was on describing and discussing the pedagogical model of PBL, the content of the program, the role of the tutor, how to organise the group work, and to set up a “co-operation contract”. Then to start the learning process, the tutor presented a situation or event (scenario). This scenario consisted of a short text (but it could also have been a picture or a press cutting) about some of the areas mentioned above. The group discussed their experiences and raised thoughts.
Then they decided together which aspects of the described situation they wanted to focus on in the future. They drew up a list of priority areas of concern. A structured problem-solving process was used to stimulate the individuals to be active in discussions, asking questions, activating prior knowledge, and appraising the newly gained knowledge and its applicability in their own lives [114, 120]. The used structured problem-solving process was “1) Scenario, clarify terms and concepts, 2) Brainstorming, 3a) Organise in problem areas, 3b) Scrutinise and evaluate knowledge, 4) Select one or more questions, 5) Specify learning needs, 6) Self-studies, 7) Discuss, scrutinize and synthesise newly-acquired knowledge, 8) Apply newly-acquired knowledge in your own life, 9) Evaluation, 10) Continue problem-solving” [114] (p. 326).

In order to clarify that it was self-directed learning, each individual wrote targets for their learning and self-care activity changes in a workbook. The tutors gave suggestions about how and where to search for learning materials. The group had in addition to the self-directed learning an opportunity to ask a resource person in rheumatology care, such as a physician or a physiotherapist, to come to a meeting and answer specific questions. This was not used but a physician, a specialist in chronic musculoskeletal pain, gave a lecture which was based on questions from all the groups.

The tutor

Three nurses were trained in PBL and each nurse was a tutor for two or three groups. The tutors did not have the traditional role of teachers or experts, but their roles were to support the participants in the problem-solving process. The content of the work in the groups was not guided by the tutor, but instead by the purpose of PBL-program. The tutors had extensive experience as nurses and were used to providing care to individuals with rheumatic diseases. This meant that there was knowledge to address the problems that might arise. The tutors received support once per month in the educational process but also when needs were aroused.
Data collection

Study I
In study I a postal questionnaire with two postal reminders was sent to the selected sample in 1995 and in 2003. This “Epipain” questionnaire [17] included the SF-36 (see page 41). The questionnaire also had an overall key question on chronic musculoskeletal pain experience, *Have you experienced pain lasting more than three months during the last twelve months?* It was explained in an introduction that the pain should be persistent or regularly recurrent in the musculoskeletal system. The questionnaire also assessed factors that had been proposed by previous studies to influence the effect on HRQL, such as socioeconomic status [17, 124], being an immigrant [17], emotional support [17], regular exercise [125, 126], quality of sleep [127-129], smoking [17, 130, 131] and alcohol habits [17, 132].

Study II
In study II there was a cover letter, an informed consent and a questionnaire sent to the individuals one week after discharge from the hospital for rheumatic diseases. The informed consent and, if they decided to participate, the completed questionnaire was returned. If no reply, a reminder was done by a telephone call four weeks after the discharge. A similar procedure was carried out at the 12 month follow-up after completed rehabilitation.

The results from study I influenced the choice of variables that could be health promoting factors, but it was very difficult to find Swedish validity and reliability tested instrument measuring health factors. All identified measuring instruments were not possible to include in the study as a whole because of the large number of items. The aim of study II was decisive in the selection of items from these measuring instruments regarding diet, exercise habits and feeling sexual lust. The questionnaire consisted of the following question areas: HRQL (SF-36, see page 41), feeling painless (study specific question), sleep structure [17, 127, 128], feeling rested [17, 127, 128], diet [133], exercise habits [134], performing hobbies (study specific question), feeling sexual lust [135], SOC (SOC, see page 42), social support (SNASS; see page 40) and alcohol habit [17]. The demographic variables were sex, age, civil status, immigrant status, education, work capacity, socioeconomic status (main and current occupation) and rheumatic disease.
Before study II started the questionnaire was tested on 24 other individuals with a variation in sex, age, and occurrence of disease or not. Thereafter some minor adjustments were made in the layout of the questionnaire and some study specific questions were clarified to reduce the risk of misinterpretation.

**Study III**
The participants in study III received verbal information through a telephone call from one of the researchers and then the written information was sent by post to them. All the participants decided the date, time and place for the interview. Then according to a phenomenological approach the research interviews needed to be guided by openness and adherence to the phenomenon under study [123, 136, 137]. An unstructured interview without beforehand framed questions was therefore used in study III. All interviews started with an initial question, "Can you tell me about any situation where you felt that something you did was improving your health?" This initial question was relatively simple as well as easy to understand and respond to. The purpose of this question was to get the participants to feel comfortable with the situation and that they could speak openly with the researcher about their lived experiences. In order to reach depth in data and let the participants reflect over their answers there were asked follow-up questions like, “How do you think when you say ....?” and “What does it mean for you?” [123, 138].

All the interviews were carried out in an undisturbed place in the participants’ homes or at the hospital for rheumatic diseases but not in connection with any visit to caregivers. These interviews lasted between 80 to 135 minutes and were tape recorded. The interviews were transcribed verbatim [138].

**Study IV**
A cover letter, an “inclusion questionnaire” and an informed consent were sent by post to 800 registered individuals at the hospital for rheumatic diseases. The completed informed consent and the “inclusion questionnaire” were sent back to the researcher. In case of no answer after three weeks, a reminder was done with a telephone call by the researcher. A similar procedure was carried out at all three study tests.
The pre-test and one-week and six month post-tests after the one-year PBL-program were conducted by completion of a questionnaire with various validity and reliability tested measuring instruments. The results from studies I, II and III influenced the choices of measuring instruments. The areas covered were HRQL (SF-36, see page 41), empowerment (SWE-RES-23, see page 41), self-care (ASA-A, see page 41), SOC (SOC, see page 42), chronic musculoskeletal pain (visual analogue scale = VAS), quality of sleep [17, 127, 128] and fatigue (VAS). The demographic variables were sex, age, civil status, education, residence, socioeconomic status (main and current occupation) and rheumatic disease.

The participants in the experimental group also completed a questionnaire consisting of 18 questions about the quality of the PBL-program at the one-week post-test. This questionnaire consisted of questions about, for instance, the content of the PBL-program, the problem-solving process, the learning process, the group process and lifestyle changes. Most questions had five possible scores ranging from a “very small degree” to a “very large degree”.

**Measuring instrument**

**Emotional support**

*The Social Network and Social Support Scale (study II)*

The SNASS is a questionnaire used to assess social network and social support and consists of 19 items. The 10 items that affect emotional support and practical assistance as well as an item about which persons that provide support were included in the present study. The score for each of the 10 items ranged from; Yes, absolutely=one point, Yes, partly=two points and No=three points. A lower score indicated a strong emotional support and practical assistance. SNASS has demonstrated good reliability and validity [139, 140].
Empowerment

The Swedish Rheumatic Disease Empowerment Scale (study IV)
The SWE-RES-23 is a new questionnaire with five subscales assessing different aspects of empowerment: subscale 1 – Goal achievement and overcoming barriers to goal achievement, subscale 2 – Self-awareness, subscale 3 – Managing stress, subscale 4 – Assessing dissatisfaction and readiness to change, and subscale 5 – Support for caring. The items are scored on a five point Likert scale ranging from strongly disagree (1) to strongly agree (5). A higher value indicated a stronger empowerment. SWE-RES-23 has demonstrated acceptable reliability and validity [141].

Health-related quality of life

The Short Form-36 health survey (studies I, II and IV)
The SF-36 is a general questionnaire used to assess HRQL. The SF-36 gives eight subscales assessing different aspects of HRQL: Physical Functioning (PF), Role – Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role – Emotional (RE) and Mental Health (MH). The score for each of the eight subscales ranged from 0 to 100. A higher score indicated better health [54]. The Swedish version of the SF-36 has shown good reliability and validity [142-144].

Self-care activities

The Appraisal of Self-Care Agency Scale (study IV)
The ASA-A is a questionnaire based on Orem’s self-care deficit theory of nursing. The ASA-A has 24 items which assess the self-care abilities. A Likert scale is used with five response categories. The total range of the ASA-A scale is 24 to 120 points. A higher score indicates better self-care ability [145]. The Swedish version of the ASA-A has demonstrated good reliability and validity [146, 147].
Sense of coherence

The Sense of Coherence (study II and IV)
The SOC is a questionnaire based on Antonovsky’s theory of sense of coherence. The SOC is used to assess the sense of coherence, measured by comprehensibility, manageability and meaningfulness. The version with 13 items was selected [5, 148, 149]. The score for each of the items ranges from 1 to 7. The total range of the SOC scale is 13 to 91 points. A higher score indicates better/stronger SOC [5, 148]. This shorter Swedish version of the SOC has shown good reliability and validity [40, 150].

Data analysis

Statistical analyses (studies I, II and IV)
In studies I, II and IV the statistical analyses were done with SPSS for Windows, Release 15.0, 17.0 and 18.0 respectively. The independent-samples t-test was used for statistical comparison of means. The Chi-square test was used for comparison of prevalence between groups. In studies I and II the associations between the dependent variables (SF-36 subscales) and independent variables were estimated by OR and their 95% CI calculated by multivariable logistic regressions for all independent variables (study I) or for each of the independent variables at a time (study II) with adjustment for age, sex and baseline SF-36 values. The SF-36 scores were dichotomised with regard to the mean values in the population for each subscale (1 ≥ mean and 0 < mean). The analyses were done with simple contrast to a reference group for each of the independent variables. At baseline in study I the analyses were checked for interaction between sex and age and all of the independent variables. Participants with missing values for any of the variables were rejected from the analyses. The actual number of participants in each analysis was considered to fulfil the requirement of at least 10 participants in the outcome for each independent variable. A $p$-value of less than 0.05 was considered statistically significant in all of the studies but because of the many comparisons in study II $p$-values showing a weak significance (>0.01) may appear by chance. In study II a power-calculation
showed that at least 150 individuals would be enough at a 5% significance level to provide at least 80% power in the current analyses. In study IV the power calculation with a 25% possibility of dropouts showed that 150 individuals in the experimental group and 390 individuals in the control group would be enough. In this pilot study the group size of 54 individuals in the experimental group and 148 in the control group was therefore approximately one third of the estimated number of participants in the power calculation. The power calculations in studies II and IV were based on the analysis of the SF-36 vitality scale and a power of more than 80% for a two-tailed test, a significance level of 5% and an assumption that the minimum difference between the groups was 6 points and a maximum standard deviation was of 20 points [151]. The actual number in study IV though was sufficient to detect a clinical relevant minimum difference of 10 points with a power of 88%.

Phenomenological analysis (study III)

Study III has a Husserlian phenomenological approach [152] based on a reflective life-world perspective [153]. The purpose of a phenomenological reflective life-world perspective is to come close to and describe the essence or general structure of the phenomenon in a clear and comprehensible way to expand and deepen the understanding about the individual’s lived experience [123, 137].

The descriptive analysis of the data material in study III followed the phenomenological approach as described by Giorgi [136, 137] and Dahlberg et al. [123]. Initially, in order to get an overall impression of the material the interviews were intercepted and read several times until the researchers felt familiar with the material. The sense of the whole was important before starting to examine the parts. Subsequently each transcribed interview was divided into smaller parts, meaning-bearing units, in relation to the studied phenomenon health-promoting self-care. Based on the variations of differences and similarities, the meaning-bearing units were organised in order to see and understand patterns, clusters of meanings. As the analysing process moved forward from concreteness to a more abstract level of understanding the clusters of meanings were synthesised into a structure or pattern in which they were bound together. In this phase the essence of the phenomenon health-promoting self-care started to emerge. The essence, the
very core of the phenomenon, and its constituents with an aim to describe and clarify the essence were thus analysed in relation to each interview, meaning-bearing units and clusters of meanings. The constituents could not be separated; they were intertwined with each other as well as with the essence. According to a phenomenological approach, data were openly analysed by flexible moving between the whole – the parts – the whole of the interviews [123, 136, 137].
Methodological considerations

To obtain a broader understanding of health promoting factors in people with and without musculoskeletal pain and in people with rheumatic diseases, a multiple method design was used including a combination of quantitative methods (studies I, II and IV) and a qualitative method (study III). It is now accepted and possible to combine quantitative and qualitative approaches and come up with rich results. Quantitative and qualitative research complements each other because they generate different kinds of knowledge of how the world is organised and classified, epistemology, which can give a deeper understanding of the nature of the world, ontology [154-156]. It is important to do high-quality research whether the researcher uses quantitative or qualitative methods. Scientific rigor is associated with the worth of research outcomes, the trustworthiness. The trustworthiness is defined differently for quantitative and qualitative research and different procedures are needed to achieve it [122, 157]. Internal validity, external validity, reliability and objectivity were considered in the quantitative studies (studies I, II and IV) and credibility, transferability, dependability and confirmability in the qualitative study (study III) in this thesis.

The trustworthiness in the quantitative studies (studies I, II and IV)

Internal validity

Internal validity is “the extent to which it is possible to make an inference that the independent variable is truly causing or influencing the dependent variable” [122] (p. 246). History and maturation can be threats to the internal validity if there are events or other changes that can influence the results. If the participant can remember an earlier test maybe this memory may influence the participant to change attitudes or increase their knowledge in the test. Another threat is the instrumentation which refers to changes in the measuring instrument or measurement procedures over time. The selection of participants can be a threat regarding which participants are chosen and how they are grouped [122, 157]. The history and maturation threats in studies I and IV were supposed to affect all of the randomised groups and
were therefore not a typical threat. In study II there was a history and maturation threat that was taken into account when interpreting the results. In studies II and IV the majority of the measuring instruments were generic, had good validity and could be applied in a wide range of settings [52]. In study II some questions were also selected from reliability and validity tested measuring instruments. These questions have been frequently used in other studies but not separately from the measuring instruments. These questions cannot be said to be reliability and validity tested when used standing alone. Neither were the study specific questions reliability and validity tested. The instrumentation threats were after all considered to be small because the items were not changed during the studies. The researchers were also the same in each study and there were clear instructions on how the data collection would go on. The threat of the selection of participants was present in studies I and IV when comparing groups, but the threat was probably small in both studies because of the random assignment. The dropout of participants could also serve as a threat to the internal validity. In study I, an analysis of non-responders in 1995 of the population had been done in a prior work [17]. It was found that people with chronic musculoskeletal pain were more prone to respond than people without musculoskeletal pain giving a higher estimate of the prevalence. This is not likely to bias the results in the follow-up of the population. Between 1995 and 2003 there were 93 participants that were either deceased or had moved abroad. This could be a threat to the internal validity. In study IV the dropout was 25% in the experimental group and there was a risk that only the most “healthy” and motivated individuals with rheumatic diseases participated and completed the PBL-program. In study II all of the participants received rehabilitation for three weeks at the same hospital and a threat could be that the rehabilitation program was different depending on the participant’s problems and resources.

**External validity**

External validity is “the extent to which study findings can be generalized beyond the sample used in the study” [157] (p. 218). Threats to the external validity are if the results only are meaningful for the group being studied. Replication of the results in another study strengthens the external validity [122]. In study I the population was people with and without chronic
musculoskeletal pain and in study II the population was people with rheumatic diseases and these two different populations showed that some of the most important health factors were identical which could strengthen the external validity. The population in study IV was small and the external validity has to be strengthened by a replication study.

Reliability
The reliability is “the degree of consistency or dependability with which an instrument measures an attribute” [122] (p. 566). It is the stability, internal consistency and equivalence that are of interest when studying the reliability. Assessment of the stability of an instrument is made by test-retest reliability procedures. Internal consistency is an assessment if subparts of an instrument are measuring the same attribute. Equivalence is an assessment of the degree to which two or more independent observers agree about the scoring on the instrument [122, 157]. In studies I, II and IV the reliability was not tested for any measuring instruments, but in the selection of measuring instruments the focus was on finding instruments with known good or acceptable reliability and validity to prevent a threat. With regard to some items in study II, see the internal validity at page 46.

Objectivity
The objectivity is “the extent to which two independent researchers would arrive at similar judgements or conclusions (i.e., judgments not biased by personal values or beliefs)” [122] (p. 562). In study I the researchers did not know the participants but in studies II and IV the researchers could have had some contact with the participants although not at any deeper level. The researchers strove to be as objective as possible in the data collections and in the data analyses. All statistical analyses were discussed and judged by all the researchers involved but also with a statistician to prevent a threat to the objectivity.
The trustworthiness in the qualitative study (study III)

Credibility
Credibility is “a criterion for evaluating integrity and quality in qualitative studies, referring to confidence in the truth of the data” [122] (p. 551). In study III the phenomenological method was chosen due to its openness and strength in describing experiences without attempting to interpret those [123]. The credibility was strengthened when one of the researchers scrutinised every transcribed interview before the next interview was made by the interviewing researcher to be sure that the questions in the interviews were in accordance with the aim of the study. Leading questions were avoided and the participants were allowed to freely narrate their experiences. The interviews were characterised by openness and pliability with the participants. The sample size was not decided on beforehand but was determined from to what extent the participants had the ability to provide rich and deep data. Quotes from the interviews were given to clarify and illustrate the analysis. All researchers had different professional, clinical and theoretical backgrounds and were involved in most steps of the study. The researchers’ personal beliefs, theories and assumptions were always put under consideration and critical reflection in order to encounter the phenomenon in an open manner [123, 136, 137].

Transferability
Transferability is “the extent to which qualitative findings can be transferred to other setting or groups” [122] (p. 570). Twelve individuals were interviewed in study III which could be seen as a small number of participants, but the interviews presented a rich description of meanings of the phenomenon health-promoting self-care. The rich presentation of the results together with appropriate quotations also enhances the possibilities of transferability. The researchers were therefore inclined to believe that the results are of interest to health-care professionals and other people with rheumatic diseases.
Dependability
Dependability is “a criterion for evaluating integrity in qualitative studies, referring to stability of data over time and over conditions” [122] (p. 552). In qualitative research the intention is to have others to concur that the results are sensible and consistent with the collected data [123]. To strengthen the dependability in study III two of the researchers, which were familiar with the method, began to analyse the data separately and then compared the findings. After that, all the researchers compared the findings to prevent a threat to the dependability.

Confirmability
Confirmability is “a criterion for integrity in a qualitative inquiry, referring to the objectivity or neutrality of the data and interpretations” [122] (p. 550). It is essential for researchers to reflect on their role both in the data collection and in the data analysis. The interview is shaped by both the interviewer and the participant while the participant chooses what he or she wants to share [123, 138]. In study III all the interviews were carried out by one researcher in an undisturbed place in the participants’ homes or at the hospital for rheumatic diseases but not in connection with any visit to caregivers. This researcher also worked as a rheumatology nurse who probably influenced the interview situation, but the participants had never been cared for by the researcher. The researcher’s background helped to reach a depth in the interviews by sensing which follow-up questions to ask. The background was also a limitation in that it was sometimes difficult to bridle the pre-understanding and to know whether the researcher would have asked for more details. However, the researchers tried to consider the confirmability in all stages of the study when the researchers restrained or bridled their pre-understanding due to, for instance, their experiences of working with rheumatology care, living with a rheumatic disease or having relatives or friends who were living with a rheumatic disease. The researchers actively reflected their pre-understanding individually but also all together to prevent a threat to the confirmability [122, 123].
Ethical considerations

The studies in this thesis were conformed to the principles outlined in the Declaration of Helsinki [158] and national codes of ethics in Sweden [159]. Approval from the Regional Ethical Review Board in Lund, Sweden was obtained for all studies (study I – ref. 389-94, study II – ref. 566/2006, study III – ref. 566/2006, and study IV – ref. 560/2008). The Swedish Data Inspection Board approved the computerised registration in study I (ref. 6623-94). Study IV was also registered at http://clinicaltrials.gov with the identifier number NCT00803491. Clinical Trial.gov is a registry of federally and privately supported clinical trials conducted in the world for a wide range of diseases and conditions. Studies II, III and IV were also approved by the operations manager at the hospital for rheumatic diseases. All four studies adhered to the four main ethical research demands: information, consent, confidentiality and utility [160].

In all of the studies the participants were personally invited to take part in the study by a written letter including readable information about the background, aim, method, the potential risk of the study, but also the opportunity to withdraw from the study without any consequences to the participants’ current or future care. In studies I, II and IV written information was sent by post to the populations. In study II it was also possible for the participants to telephone one of the researchers to obtain verbal information about the study. The participants in study III received verbal information through a telephone call by one of the researchers. After this telephone call written information was sent by post. In study IV verbal information was given to individuals who called the researchers. It was also common with verbal information when the researcher called the individuals who had not sent any answer after three weeks. It was not unusual that the individuals were waiting for the call to get more information. Informed consent was obtained from all participants in studies II, III and IV before the data collections started.

All information from the participants in the studies has been treated with great respect for the participants’ privacy and autonomy [161, 162]. All of the documents from the studies were handled to guarantee confidentiality. Every questionnaire in studies I, II and IV and interviews in study III were
coded with a corresponding number to protect the anonymity of the participants [161]. Personal information was recorded according to the Swedish Personal Data Law (1998:204) [163] in consultation with the data protection officer at the research centre. Only researchers involved in the studies had access to the data material [161]. The data materials were stored and kept locked away at the research centre according to the Swedish Archives Law (1990:782) [164].

In all of the studies the risk of causing emotional or psychological problems to the participants by the interview or questionnaires was considered. In contact with the participants, much emphasis was to meet them with respect and with an open and flexible attitude [161]. The participants were also able to contact the researchers by telephone, letters or e-mail whenever they wanted. Health-care professionals in the hospital for rheumatic diseases were informed about the studies (studies II, III and IV) and were thus an essential additional resource for unforeseen discomforts for the participants. The tutors in the intervention study (study IV) had extensive experience as rheumatology nurses and were used to providing care to individuals with rheumatic diseases. This meant that there probably was knowledge to address problems that might arise.

In study III there was no dependent relationship between the researcher and the participants because the participants had not been cared for by the researcher [161]. All of the participants decided the date, time and place for the interview. The interviews were tape recorded and then transcribed verbatim by one of the researchers. The translation of the results into English was made carefully by a translator, so the original meaning in the quotations was not altered.

In study IV all of the participants received standard care for people with rheumatic diseases. To enable the participants to get the same opportunity to join the PBL-program, a randomisation to either the experimental group or the control group was done. A note with the letter E or C was placed in a sealed envelope. These envelopes were then mixed and put in a box. When the researchers received a completed pre-test questionnaire the first envelope was picked from the box. One of the researchers then called the participant and informed how the randomisation had gone. During this call verbal information about the study was also given but also information about the PBL-program to the participants in the
experimental group. A limitation was that the PBL-program only could be held at the hospital for rheumatic diseases and that no economic compensation could be given to the participations for the travels or the need to take time off work. Another limitation in all of the studies was the exclusion of individuals not speaking or reading Swedish. This means that the results are not applicable to these people in Sweden [161].

The researchers frequently discussed the researchers’ influence on the participants but also how to manage the data in an ethical manner. The results of the studies in this thesis were presented at group level and which thereby minimised the risk of personal identification and risk of harm [161]. The usefulness and beneficence of the studies were deemed as greater than the risks for the participants. The participants in study III have received and the participants in studies II and IV will receive a summary of the results from the study in which they participated. All results in this thesis will also be reported at the hospital for rheumatic diseases in which the studies were conducted.
Summary of results

Health predicting/promoting factors in a general population (study I)

In study I people without chronic musculoskeletal pain scored statistically significantly better than people with chronic musculoskeletal pain in all eight SF-36 dimensions both at baseline and at the eight-year follow-up (Figure 3). The scores for all SF-36 dimensions statistically significantly deteriorated over the eight-year follow-up for people without chronic musculoskeletal pain. The changes were more complex for people with chronic musculoskeletal pain: significantly worsening for PF, SF and RE, significant improvement for BP, and no significant changes for RP, GH, VT and MH.

Figure 3 The SF-36 scores for people with and without chronic musculoskeletal pain in 1995 and 2003.
Comparison of the SF-36 subscales scores (mean values) for people with and without musculoskeletal pain at baseline in 1995 and at follow-up in 2003.
The association between suggested health factors and baseline SF-36 mean scores and the predictive value of these health factors with regard to SF-36 development over eight years was estimated with multivariable logistic regression analyses controlling for sociodemographic characteristics. Results from the multivariable logistic regressions with OR and 95% CI for these variables are found in the published article (study I) in the back of this thesis.

Similar health factors were found to be associated to a higher score in health at baseline and also predicted a better outcome in an eight-year follow-up both in participants with and without chronic musculoskeletal pain. The most consistent finding was a better health outcome in the eight-year follow-up for participants that were feeling rested after sleep. Other factors that in some aspects predicted a better outcome, controlled for age and sex, were belonging to a higher socioeconomic group, being a native Swede, having emotional support, having a good sleep structure, never being or being a former smoker, and regularly drinking alcohol.

Although the multivariable logistic regression analyses were not intended to be complete explanatory models, at baseline 8.2-32.7% (Nagelkerke R²) of the variance in the dependent variables could be explained by the predictor variables for participants without chronic musculoskeletal pain. The figures were between 16.4-30.9% for participants with chronic musculoskeletal pain. In the eight-year follow-up it was 14.5-40.9% for participants without chronic musculoskeletal pain and 26.3-49.5% for participants with chronic musculoskeletal pain.

Factors promoting HRQL in people with rheumatic diseases (study II)

In study II the focus was on the effect of proposed health factors on the long-term outcome in HRQL in people with rheumatic diseases that have undergone inpatient rehabilitation. There were significant deteriorations in seven of the SF-36 dimensions (PF, BP, GH, VT, SF, RE, MH) between one week and 12 months after the rehabilitation (Figure 4).
The promoted value of the suggested health factors with regard to SF-36 development over 12 months was estimated with multivariable logistic regression analyses where each of the health factors was controlled for sex, age and baseline SF-36. Results from the multivariable logistic regressions with OR and 95% CI for these variables are found in the article (study II) in the back of this thesis.

The health factors that proved to affect most subscales in HRQL in a positive way were having a strong SOC, feeling rested after sleep, having work capacity, being younger or middle-aged, and having no or small problems with the sleep structure. The most obvious health factor was having strong SOC one week after rehabilitation promoting a positive outcome in seven of the eight SF-36 subscales (RP, BP, GH, VT, SF, RE and
MH) 12 months later. Another important health factor in the present study was feeling rested after sleep promoting a positive outcome in five SF-36 subscales (RP, BP, GH, VT and SF). Moderate problem with feeling rested after sleep promoted a better outcome in one SF-36 subscale (VT). Having work capacity of 25-100% promoted a health status better than the mean score in four SF-36 subscales (PF, RP, BP and MH) 12 months after rehabilitation. Being of younger age (18-51 years) was associated with a health status better than the mean score in two SF-36 subscales (PF and RE). Being 52-60 years of age significantly promoted a better outcome in three SF-36 subscales (PF, RP and RE). Another important health factor was having no or small problems with the sleep structure which promoted a better outcome in two SF-36 subscales (GH and VT). Having moderate problem with the sleep structure promoted a better outcome in one SF-36 subscale (VT).

Other health factors were feeling painless, making low effort of exercise more than two times per week, having emotional support and practical assistance, and having completed secondary school as highest education. Each of these factors promoted a better health status in only one of the SF-36 subscales.

The multivariate logistic regression analyses in this study were not intended to be complete explanatory models, but 12 months after rehabilitation 48.8-55.3% of the variance in PF could be explained by the predictor variables (Nagelkerke $R^2$) and 21.2-33.5% in RP, 14.3-25.6% in BP, 31.1-43.9% in GH, 16.6-26.0% in VT, 20.3-30.1% in SF, 28.0-40.1% in RE and 32.3-44.0% in MH.

Experiences of health-promoting self-care in people living with rheumatic diseases (study III)

In study III people living with rheumatic disease described their experiences of health-promoting self-care. In the essence of the phenomenon health-promoting self-care, self-care took place against a background of continual hope and belief in a future ability to influence health in a positive way.
Health was experienced as a harmony and to be in balance with the body as well as in all other aspects of life like the individual’s social life.

Self-care was a way of life and meant to be ready at all times to respond to signals from the body, such as tiredness, sadness, stiffness, and pain. Such signals were needed to be interpreted and understood as indicators of actions that were needed to alleviate the problem(s). Self-care meant an inner dialogue where physical, emotional, and cognitive aspects of the body were considered. It was equally a dialogue with previous social, cultural and religious memories, and experiences of life as well as with other people such as family members, colleagues and friends, mass media, and written word in books or on the Internet.

The meaning of self-care could also be described as a power struggle within the individual between the desire to be free from the rheumatic disease and the concrete fact that the symptoms indicate that the disease was a part of the body. People living with rheumatic diseases strive and force themselves to fight the illness and its concrete consequences in order to attain well-being and health. The power struggle takes place within the body between its possibilities and limitations while the meaning of the power struggle was to obtain control over the body.

The meaning of self-care was to make rewarding or beneficial choices. The choice implies a dialectic process, where previous experiences were carefully balanced against the will to change and challenge the lack of well-being caused by the diseases. Trust in oneself and belief in one’s own ability to choose health-promoting self-care was crucial for the choice. Although the choice between different self-care approaches was not always clear and straightforward, the choice was invariably aimed at generating some form of recompenses for the body related to health and well-being. Rewarding or beneficial choices increase self-confidence and self-esteem.

This essence of the phenomenon health-promoting self-care in people living with rheumatic diseases is followed by its three constituents, dialogue, power struggle and choice, which describe and clarify the essence. These constituents are described and illustrated by quotations from the interviews in the article (study III) in the back of this thesis.
Effects of a self-care promoting PBL-program as reported by people with rheumatic diseases (study IV)

This study focused on evaluating the effect of the self-care promoting PBL-program for people with rheumatic diseases who have chronic musculoskeletal pain, sleep disturbances and/or fatigue, in terms of HRQL, empowerment and self-care ability. All values of the mean, SD, mean differences, 95% CI and p-values are found in the article (study IV) in the back of this thesis.

There were no statistically significant differences between the experimental group and the control group and SF-36 subscales measuring HRQL, at the pre-test, the one-week post-test and the six month post-test.

Empowerment as measured by the SWE-RES-23 showed statistically significant differences between the experimental group and the control group. At the six month post-test the experimental group scored statistically significant higher means than the control group in the SWE-RES-23 total score and in two SWE-RES-23 subscales, subscale 2 - Self-awareness and subscale 3 - Managing stress.

There were no statistically significant differences between the experimental group and the control group in any of the tests in terms of self-care ability measured by ASA-A or SOC, feeling pain the last week, feeling fatigue the last week, not falling asleep at night, waking during the night, not feeling rested after sleep or waking too early.

The participants in the experimental group stated that they had belonged to a group that worked well together to a fairly high degree (n=15, 39.5%) or to a sufficient degree (n=10, 26.3%). The participants described that they felt involved, felt a community and security in the group, and that it was interesting to exchange experiences and knowledge. They also described that all participants were not enough active or engaged enough. The dropouts and absences disrupted the work in the groups. The participants had implemented lifestyle changes to a fairly high degree (n=8, 21.1%), to a sufficient degree (n=17, 44.7%) or to a fairly small degree (n=9, 23.7%) during the PBL-program. Examples of lifestyle changes were trying to think more positively, thinking of themselves, being more physically active,
changing in sleeping habits and food habits, reducing the use of pills and reducing smoking. The participants stated that they had implemented these lifestyle changes to a very small degree (n=9, 23.7%), to a fairly small degree (n=14, 36.8%) or to a sufficient degree (n=12, 31.6%) without the PBL-program.
Discussion

This thesis which has a salutogenetic approach describes that people with and without chronic musculoskeletal pain (study I) and people with rheumatic diseases (study II) had some similar health promoting factors like feeling rested after sleep and having a good sleep structure. Having strong SOC and work capacity (regardless of the number of working hours) were also important health promoting factors for people with rheumatic diseases (study II). People with rheumatic diseases also experienced the meaning of health-promoting self-care as that the self-care took place against a background of continual hope and belief to influence their own health in a positive way. Self-care was a way of life and implied being ready to understand and respond to signals from the body (study III). Then when testing a self-care promoting PBL-program (study IV) it enabled people with rheumatic diseases who have had the disease for more than a year and had chronic musculoskeletal pain, sleep disturbances and/or fatigue for at least three months to improve their empowerment and implement lifestyle changes.

Globally, the discussions about health factors have increased the last decades and the EU states that the most important health factors are people’s social and economic conditions but also diet, exercise and how people treat themselves and others [51]. What is not mentioned by the EU are the factors feeling rested and sleep which have been shown in this thesis to be important health factors. Why the importance of these factors have not received attention is difficult to explain even if the average individual usually knows their importance. Earlier studies have shown that tiredness and fatigue are very common symptoms in individuals with for example RA [72, 73, 165, 166]. Fatigue is a subjective symptom that worries the individuals and it is important to help the individuals to express concerns about fatigue as well as to help them to improve it and hence their HRQL [167, 168]. Other studies have also shown that there is a high prevalence of insomnia in general populations [169-171] and that insufficient sleep has been associated with impairment of HRQL [129] but also with frequent pain [129, 172, 173]. The conclusion of a review is that good sleep is vital for health and HRQL, but the role of sleep is unfortunately not well explored [174] and this thesis
confirmed that there must be a change. There is a great need for more research about the importance of sleep but also how to relieve sleep disturbances and fatigue without drugs. Unfortunately it was not possible to show that a participation in the PBL-program could improve the participants’ sleep and fatigue. Neither did the self-care ability show any statistically significant differences, but still it was two-thirds of the participants who stated that they had implemented lifestyle changes in a fairly high or sufficient degree during the PBL-program. These lifestyle changes were, for instance, to try to think more positively, to think of themselves, be more physically active, change in sleeping habits and food habits, reduce the use of pills and reduce smoking. The PBL-program seems to have stimulated mainly some inner resources (GRR) of the participants and made the resources visible and possible to use (SOC). The PBL-program, however, did not affect the participants’ SOC which confirms Antonovsky’s theory that it is difficult to influence the SOC, but it is quite possible that the effect would have been different if external resources such as the family had been included in the PBL-program.

People living with rheumatic diseases experienced the meaning of health-promoting self-care as self-care being a way of life (study III). It meant to be ready to understand and respond to signals from the body. This finding agreed well with Orem’s self-care theory which describes self-care as a process. This process consists of actions of investigating, formulating and expressing requirements but also making judgements about what should be done. When individuals perform actions it requires essential power which is activated through stimuli [84, 85]. In study III self-care was described as a power struggle between the individual and the rheumatic diseases but also in relation to other people. The power struggle was within their body between its possibilities and limitations and the meaning was to obtain control over the body. This result was confirmed by Öhman et al. who showed that people with serious chronic illness experience the body as a hindrance and that they were struggling for normalcy [175]. Králík et al. [86] and Taylor [89] demonstrated that self-care was a constant planning and managing of daily life as a meaning of creating order. This meant that actions to initiate order or obtain control were not a single act. Instead, it was a combination of processes carried out over a period of time. In study IV the participants scored increased empowerment after participation in a one-year self-care
promoting PBL-program. Empowerment is described as a continuous variable and the strength and direction of change shows the intervention’s effectiveness [78]. Further, empowerment is described as a multi-dimensional social process that could help people to gain control over their own lives [77]. An empowerment approach means that the participant is involved in problem formulations, decision making and actions. Thus, the health-care professionals have to refrain some of their control and power over, for instance, the participant’s disease and treatment [74]. Three-fifths of the participants in study IV also stated that they had implemented the lifestyle changes to a very small or fairly small degree without the PBL-program. These results agreed well with Andersson et al.’s description that an empowerment based intervention involving facilitating and supporting the participants to reflect their experiences could enhance the participants’ awareness and consequences of self-care decisions [78].

When people with rheumatic diseases were going to do self-care they were required to make choices. The essential means of these choices were to generate some form of reward for their body in order to increase the possibilities to improve well-being and health. These choices in turn required that previous experiences were balanced carefully against the desire to change and challenge the lack of well-being caused by the diseases (study III). This agreed well with the findings from Kralik et al. where people learned about their responses to diseases through experiences and as a result of trial and error. They learned about their personal limitations or boundaries and could then make decisions on how they should plan and prioritise [86]. In order to experience good health, people with various disabilities need the ability to build and maintain a sense of balance between body, mind and spirit as well as between their social context and environment [176]. This agreed well with the findings from study III where the individuals experienced health as a harmony and to be in a balance with the body. The body means a unit of the physical body and soul as well as the individual’s social life. The individuals experienced that the body could not be shared in various parts - everything was connected. Their experiences agreed well with Merleau-Ponty’s philosophy where the physical and the psychological are described as an interwoven unit, the lived body. The lived body is then in constant interaction with the world [153].
To make health-promoting self-care it required trust in oneself and belief in one’s own ability to make choices (study III) and this was also reflected in study II where the most obvious health factor was having strong SOC for people with rheumatic diseases to promote a positive outcome in HRQL 12 months after the rehabilitation. It has also been shown that SOC has a major influence on the HRQL of people with SLE. The individuals with strong SOC had the ability to predict, explain and cope with disease related stressors and achieve a better HRQL [48]. According to Antonovsky the individual had a greater ability to stay healthy if the individual experiences life as comprehensible and manageable while finding a sense of meaningfulness in dealing with problems [5]. It has also been shown that high self-esteem was promoting a responsible self-care behaviour style [177]. A feeling of togetherness and fellowship emerge when being in dialogue with others in study III and two other studies found that the individuals acquired a power of life from people around them [100, 178]. This was also in agreement with Malterud and Hollnagel’s findings where personal and social resources were essential means for tolerating and managing the burden of diseases [92]. Emotional support was also found to be important for a better HRQL for people with chronic musculoskeletal pain (study I) and also to some degree after rehabilitation for people with rheumatic diseases (study II). Others have also reported that having emotional support increases HRQL [17] and emotional support is very important for the possibilities to handle a disease such as RA and its consequences [178].

Other external factors, like employment and having financial support, have also been shown to be important to secure health. The external factors were strongly linked to the perceptions of normality [179]. This was confirmed in study III when the participants raised a sense of being like others and being needed. It has been shown that people with RA who perform a paid work scored better HRQL than people with RA who were not working due to disability pension, retirement or being student or home workers [180]. Work ability was also indicating better HRQL in people with SLE [60] and in people with different rheumatic diseases (study II). Factors that contribute to decisions to cease work for individuals with RA are the physical nature of the work, the workload, the fatigue or the pain [181]. It is therefore important to help individuals to be able to continue to work
regardless of the number of work hours, but adjustments of the nature of the work and workload have to be made. Thus, increases the amount of Antonovskys’ GRR it is quite possible that the individuals’ ability to use them (SOC) increases.

It was surprising to notice that exercising regularly was not shown to be important for HRQL for either people with or without chronic musculoskeletal pain (study I). For people with rheumatic diseases who were making a low effort of exercises more than two times per week, it was a weak promoter to improve HRQL (study II). This is not in accordance with some previous studies that have shown a positive association between exercise and health [125, 126], but the effect of exercise is complex because some studies show that exercise has no effect on health [182-185]. However, there is nevertheless more evidence that exercise is beneficial than risky to the health [185] and the evidence of the effect on health for other self-care interventions has been even more absent or weak [186].

In study III the findings showed that the meaning of self-care was much more than exercise for people with rheumatic diseases. Self-care was an internal dialogue within the body but also an external dialogue with the immediate environment. In order for the individuals to perform self-care, they needed to understand how the restricted body functioned. This understanding required time, willingness, and the ability to wait in an active way until the signals emitted by the body became clearer (study III). Often there is no time in clinical practice to give individuals the opportunity to have deeper external dialogues with the health-care professionals. Instead, there is often an unspoken requirement on the individual to listen, accept and to do what is recommended [187]. It has also been shown that individuals with RA want to be informed and that they express a great need for information about the disease and its treatments [99], but they do not always understand the given information [100]. It is important that health-care professionals find ways of checking the level of individuals’ understanding and only after that they could support and empower the individuals to do self-care [100]. In terms of lifestyle changes Fontaine et al. have shown that it is fewer than two-fifths of the individuals with arthritis who are reporting that they are meeting the public health recommendations for physical activity [188]. Knowledge and understanding are the main factors for better self-care in general populations. Health-care professionals but also family
and friends are important sources to give information, guidance and support health-promoting self-care [82].

The important health information is normally not enough by itself. It usually requires different methods to support people to make healthy choices in their everyday lives [51]. Study IV confirms this when the participants described both positive and negative aspects about the participation in the PBL-program. PBL was a pedagogical model which suited some participants very well but not all. It is probably difficult to create a patient education program that will fit all participants. Instead, health-care professionals should strive to create and offer the individuals several different patient education programs. The most effective patient education must be presented to the right individual, at the right time and in the most appropriate way [101]. It is therefore important that health-care professionals find ways to check the individuals’ level of understanding and only after that could they support and empower the individuals to do self-care [100].
Comprehensive understanding

In clinical practice the health-care professionals often meet people with chronic musculoskeletal pain or with rheumatic diseases who ask how to relieve the pain, the sleep disturbances or the fatigue. People with these diseases are then often offered drugs and exercise as a treatment. The results in this thesis show that health promoting factors like feeling rested, having good sleep, emotional support, work capacity and SOC should receive attention to at least the same level as exercise in rheumatology care. As health-care professionals it is possible to help people to work with and stimulate health promoting factors like feeling rested, having good sleep, emotional support and work capacity. Then, if it is possible to affect the SOC although controversial maybe a step in the right direction can be that health-care professionals adopt a more salutogenic approach instead of the usual pathogenic approach. If the individuals get help to experience, for instance, the fatigue and sleep disturbances as more understandable and manageable while finding a purpose in dealing with problems, the meaningfulness, the individuals have a greater ability to get stronger SOC and adopt factors that promote their health. This empowerment approach involves helping and supporting the individuals to learn to reflect their experiences, think critically and make informed decisions. This self-reflection leads to enhanced awareness and understanding of the consequences of their decisions about self-care. Further, people with rheumatic diseases make decisions about self-care against a background of continual hope and belief to influence their own health. Self-care is also a way of life and meant dialogues, power struggle and choices. Thus, self-care is actions of investigating, formulating and expressing requirements, but also making judgements about what shall be done to influence a person’s own health in a positive way. These actions or abilities are learned through relationships and communication with other people like relatives, friends and health-care professionals. Further, people with RA want to be informed and they express a great need for information about the disease and its treatments, but they do not always understand the given information. Then the rheumatology nurses give much information about drugs and blood tests but little about self-care to people with RA. Patient education is otherwise
one of the most important tasks for nurses in rheumatology care but rarely evaluated or studied. Also the use of pedagogical models in patient education is deficient. PBL is one pedagogical model which is associated with self-directed knowledge, critical thinking or problem-solving, manage uncertainty and communication learning and these skills are also needed by individuals with a chronic disease in order to manage their condition. It has been shown that people with rheumatic diseases have benefit from taking part in patient education with a self-care promoting PBL-program. Their empowerment is strengthened and they are implementing lifestyle changes. PBL is a pedagogical model which suited some people very well but not all. It is probably difficult to create a patient education program that will fit all people. Instead health-care professionals should strive to create and offer the individuals several different patient education programs. The most effective patient education must be given to the right individual, at the right time and in the most appropriate way.
Conclusions

The conclusions of the four studies constituting this thesis are:

- The most important health factors for both people with and without chronic musculoskeletal pain were: feeling rested after sleep, having a good sleep structure, never being or being a former smoker and regularly drinking alcohol (study I).
- The most important health factors at the 12 month follow-up for people with rheumatic diseases were: having a strong SOC, feeling rested after sleep, having work capacity, and having a good sleep structure (study II).
- Feeling rested after sleep and having a good sleep structure promoted improved HRQL in both people with and without chronic musculoskeletal pain (study I) but also in people with rheumatic diseases (study II).
- Emotional support promoted improved HRQL in people with chronic musculoskeletal pain (study I) and also in people with rheumatic diseases, but to a lesser extent (study II).
- The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to be able to influence their own health (study III).
- Self-care was experienced as a way of life and meant to be ready to listen, understand and respond to signals from the body indicating well-being or discomfort (study III).
- Three interrelated constituents elucidated the experiences of health-promoting self-care: dialogue, power struggle and choice (study III).
- The empowerment had been strengthened by the participation in a one-year self-care promoting PBL-program at the six month follow-up (study IV).
- There were no statistical differences in HRQL, self-care ability, SOC, pain, quality of sleep and fatigue between the experimental group and the control group after the self-care promoting PBL-program at the six month follow-up (study IV).
The participants in the experimental group stated that they had implemented lifestyle changes which they had not done without the self-care promoting PBL-program (study IV).

The results of this thesis contribute to evidence supporting the introduction of a more salutogenic approach in rheumatology care and research.
Clinical and research implications

In clinical practice, when caring for people with or without chronic musculoskeletal pain and for people with rheumatic diseases, it is important to pay attention to health promoting factors like feeling rested after sleep and having a good sleep in addition to the often already given advices regarding the diet, exercise and stop smoking. There is a need for further studies about how to promote a good and restorative sleep with different treatments, in order to develop strategies in clinical practice.

When time and money have to be saved in clinical practice it is important to take into account that emotional support is an important health promoting factor. In addition to emotional support from relatives and friends, the health-care professionals also have an important role in providing emotional support to people with chronic musculoskeletal pain or with rheumatic diseases. SOC is also an important health promoting factor but there is a need for more studies about how to support, strengthen and take advantage of the individual’s personal and social resources in clinical practice. These resources may have a positive effect on the work capacity, which is another very important health promoting factor in people with rheumatic diseases. It is therefore important to help individuals to be able to continue to work, regardless of the number of work hours, but with necessary adjustments of the nature of the work and workload.

In clinical practice it is also important to adopt a broader and more open approach to what self-care can mean to different people. Self-care is experienced by people with rheumatic diseases as much more than exercises. Further studies are needed about how health-care professionals can motivate individuals to perform recommended self-care activities.

Health-care professionals can experience a feeling of powerlessness and a lack of knowledge in how to improve the health experiences in people with rheumatic diseases. There is a great need for a larger range of strategies and treatments. This thesis shows that with relatively small resources and limited time a one-year self-care promoting PBL-program enables people with rheumatic diseases to improve their empowerment and to implement lifestyle changes. This is a beginning on the road to improve the effects of patient education. The next step might be to study how the family can be included in a self-care promoting PBL-program and what affect it have on
the participants. It is important to continue to develop PBL but also other pedagogical methods and measuring instruments in patient education, in order to find evidence for long term benefits of the patient education in rheumatology care.

Although health factors and self-care have received increased attention over the last decades, there is still a tremendous need for more research evidence on strategies and treatments that health-care professionals could use to help people with chronic musculoskeletal pain or with rheumatic diseases to improve their health and HRQL.
Hälsofrämjande faktorer hos personer med långvarig muskuloskeletal smärta eller med reumatisk sjukdom: en beskrivande och intervenerande studie

Bakgrund
Långvarig muskuloskeletal smärta och de reumatiska sjukdomarna är stora folkhälsovningar i hela världen [1]. I Europa förekommer långvarig muskuloskeletal smärta av måttlig eller svår intensitet hos 19 % av de vuxna [16] och i Sverige är förekomsten 34.5-46 % [17, 18]. Långvarig muskuloskeletal smärta är mycket vanligt förekommande vid reumatiska sjukdomar [21]. Det finns över 150 registrerade reumatiska sjukdomar i världen [22] och internationellt är förekomsten av de reumatiska sjukdomarna 41-53 % hos personer äldre än 65 år [24]. I Sverige har nästan en niondel av den vuxna befolkningen en eller flera reumatiska sjukdomar [25]. De reumatiska sjukdomarna varierar mycket vad gäller svårighetsgrad och komplexitet [22]. Således kan behandlingen skilja sig åt betydligt från individ till individ men de vanligaste behandlingsformerna avsett diagnos är läkemedelsbehandling och fysisk träning. Avsikten med denna behandling är att minska eller lindra symtom, undertrycka sjukdomsaktivitet och minska uppkomsten av skelettförändringar [1, 29].

Hälsa är ett omdiskuterat begrepp som till exempel kan definieras som "ett tillstånd som rör hela människan och är en upplevelse av att vara i jämvikt. Det handlar både om en känsla av inre balans och en känsla av jämvikt i relation till sina medmänniskor och till livet i övrigt" [36] (s. 49). Denna definition liknar de tankar om den salutogenetiska modellen som beskrivs av Antonovsky [37]. Antonovsky var kritisk till den patogena modellen (hur riskfaktorer påverkar hälsan) men ville inte ersätta det med en salutogenetisk modell (hur faktorer främjar hälsan). Han ville istället att de två modellerna skulle komplettera varandra [5, 7]. Enligt Antonovsky så är
den patogena modellen dikotomerad det vill säga individen är sjuk eller inte, det finns inga mellansteg. Den salutogena modellen däremot är ett flerdimensionellt kontinuum mellan välbefinnande (hälsa) och frånvaro av välmående (sjukdom), där individen ”vandrar” mellan dessa poler. Var individen befinner sig mellan polerna är beroende av vad som händer i hans/hennes liv [37]. Målet med ett salutogenetiskt arbetsätt är att stärka den enskildes resurser till att vara mer motståndskraftig mot faktorer som har en negativ påverkan [7].


Att få uppleva hälsa är mycket viktigt för personers välbefinande och det finns många faktorer som kan påverka deras hälsostatus [50]. De faktorer som påverkar hälsan kan vara riskfaktorer men även hälsofaktorer. Det finns många definitioner på begreppet riskfaktor men ingen har hittats på begreppet hälsofaktor. Detta kanske återspeglar att det hittills är riskfaktorer som har varit det centrala i forskningen [5, 6]. Hälsofaktorer kan beskrivas enligt Antonovskys GRR, det vill säga potentiella resurser (inre och yttre) som är tillgängliga för individen och som kan underlätta hälsofrämjande aktiviteter [5, 38, 39].

Inom forskning har ett stort intresse varit inriktat på hur människors liv påverkas av deras sjukdomar och behandlingar och då har begreppet hälsorelaterad livskvalitet (HRQL) använts [53, 54]. Det har visat sig att personer med långvarig muskuloskeletal smärta skattar sin HRQL mycket lågt jämfört med smärtfria personer [2, 56, 57]. Att skatta sin HRQL lågt är en gemensam faktor för personer med reumatiska sjukdomar som fibromyalgi [4, 58, 59], SLE [60-62], primär systemisk vaskulit [63-65], systemisk skleros [3, 66, 67] och RA [68-70]. Smärta, trötthet [1, 72, 73] och
sömnstörningar är några av de viktigaste påverkansfaktorerna på HRQL för personer med RA [1, 72].

Empowerment är ett begrepp som är nära relaterat till hälsa och HRQL [74, 75]. Det har inte gått att översätta empowerment med endast ett svenskt ord som täcker hela dess innehåll, utan ofta använs synonymer som bemyndigande, patientkraft, och egenmakt [95]. Empowerment skapas i relation till andra individer, det är en flerdimensionell social process [74, 75, 77]. Empowerment kan också ses som ett komplext mål till att ha kontroll över faktorer som påverkar individens HRQL [74, 75]. Att arbeta enligt ett empowerment stärkande tillvägagångssätt innebär att hjälpa individer att lära sig tänka kritiskt och fatta välgrundade beslut [78].

För att personer med långvarig muskuloskeletal smärta eller med reumatiska sjukdomar skall uppnå hälsa och empowerment så kan egenvårdsaktiviteter vara en möjlig väg [78, 80, 82]. Egenvård definieras ofta som en process som består av aktiviteter för att undersöka, formulera och uttrycka krav, men också för att göra bedömningar om vad som bör göras [84, 85]. Det som är av störst betydelse för ett bättre egenvårdsbeteende är att ge människor kunskap som de förstår. Hälso- och sjukvårdspersonal men även familj och vänner är viktiga källor till information, vägledning och stöd till egenvård [82].

En metod som hälso- och sjukvårdspersonal ofta använder när de skall stödja individer till egenvårdsaktiviteter är patientundervisning. Syftet med patientundervisningen är att individen aktivt skall delta i sin vård och ha kunskaper och färdigheter för att hantera sin egenvård på bästa sätt [10]. Reumatologisjukskötterskor har en viktig roll i att utbilda personer med RA till att klara av sjukdomen och för att öka den personliga kontrollen över sjukdomen [97]. Dock har den genomsnittliga kvaliteten på studier om patientundervisning till personer med RA inte varit så goda och de har kortsiktiga effekter på individens funktionshinder och psykiska status. Det finns inga belägg för att det skulle finnas långsiktiga fördelar med patientundervisning [12]. Det har också visat sig att det finns metodologiska begränsningar i patientundervisningen som har bidragit till det otillräckliga resultatet [102].

En strategi i patientundervisningen är gruppendervisning som har visat sig vara ett bra sätt att lära förmågan till problemlösning och egenvård [101]. Problembaserat lärande (PBL) är en pedagogisk modell för

Studiernas syfte, metod och resultat

Det övergripande syftet med avhandlingen, som hade ett salutogenetiskt synsätt som grund, var att beskriva hälsorömande faktorer hos personer med långvarig muskuloskeletal smärta och hos personer med reumatiska sjukdomar, och att utvärdera effekterna av en interventionsstudie med ett egenvårdsfrämjande PBL-program för personer med reumatiska sjukdomar som hade långvarig muskuloskeletal smärta, sömnstörningar och/eller svår trötthet.

socioekonomisk grupp, vara infödd svensk, ha känslomässigt stöd, ha bra sömn, aldrig ha rökt eller att han/hon varit rökare tidigare, och Regelbundet dricka alkohol.

Syftet med studie II var att undersöka sambanden mellan föreslagna hälsöfrämjande faktorer vid baslinjen och dess påverkan på HRQL hos personer med reumatiska sjukdomar 12 månader efter rehabilitering. I denna studie besvarade personer med reumatiska sjukdomar (n=185) ett frågeformulär en vecka efter en treveckors rehabiliteringsperiod och därefter 12 månader senare. Frågeformuläret bestod av följande frågeområden: HRQL, smärta/smärtfrihet, sömn, trötthet/utvilad, kost, motion, fritidsaktiviteter, sexuell lust, känsla av sammanhang, socialt känslomässigt stöd, rökvanor, snusvanor, alkoholvanor, immigrant, civilstånd, utbildning, arbetsförmåga, huvudsakliga och nuvarande yrke samt reumatisk sjukdom. Vid de statistiska beräkningarna utfördes chi-2 test, oberoende t-test och multivariata logistiska regressioner. Resultatet visade att faktorer som att ha en stark känsla av sammanhang, känna sig utvilad efter sömn, ha arbetsförmåga till någon grad, vara yngre eller medelålders, eller att ha en bra sömn, främjade HRQL hos personer med reumatiska sjukdomar vid 12 månader uppföljningen. Andra faktorer som att känna lägre nivå av smärta, motionera med en låg insats mer än två gånger/vecka, ha känslomässigt stöd, och att ha avslutat en gymnasieutbildning som högsta utbildning var faktorer som främjade bättre hälsa i endast någon av SF-36 åtta delskalar.


Syftet med studie IV var att utvärdera effekten av ett egenvårdsfrämjande PBL-program för personer med reumatiska sjukdomar beträffande HRQL, egenmakt och egenvårdsförmåga vid en sexmånadersuppföljning. I denna pilotstudie med en randomiserad och kontrollerad intervention var det 202 personer med reumatiska sjukdomar som ville delta. De hade haft sin reumatiska sjukdom i mer än ett år och besvärades även av muskuloskeletal smärta, sömnonproblem och/eller svår trötthet under de senaste tre månaderna samt att de ville delta i det ettåriga egenvårdsfrämjande PBL-programmet (Våga-Vilja-Veta-program = VVV-program). Av dessa personer lottades 54 deltagare till experimentgruppen och 148 deltagare till kontrollgruppen. VVV-programmet gavs till deltagarna i experimentgruppen upptill den reumatologiska standard vården och deltagarna i kontrollgruppen fick endast reumatologisk standard vård. Sex månader efter avslutad intervention var det 38 deltagare i experimentgruppen och 124 deltagare i kontrollgruppen.

Varje deltagare i experimentgruppen var med i en grupp bestående av sju till åtta deltagare och en handledare som var sjuksköterska. Varje grupp träffades under 1 ½ timme, 10 gånger under ett år. En läroplan för VVV-

Alla deltagarna i både experimentgruppen respektive kontrollgruppen besvarade ett frågeformulär före, en vecka och sex månader efter avslutat VVV-program. Frågeformuläret bestod av följande frågeområden: HRQL, egenmakt (empowerment), egenvård, känsla av sammanhang, långvarig muskuloskeletal smärta, sömn, trötthet och demografiska variabler som kön, ålder, civilstånd, utbildning, bostadsområde, huvudsakliga och nuvarande yrke samt reumatisk sjukdom. Vid de statistiska beräkningarna utfördes chi-2 test, oberoende och parade t-test. Resultatet visade att vid sexmånadersuppföljningen rapporterade deltagarna i experimentgruppen starkare egenmakt (empowerment) efter deltagandet i det egenvårdsfrämjande VVV-programmet jämfört med kontrollgruppen, som
endast fick reumatologisk standard vård. Det fanns inga statistiska signifikanta skillnader vad gällde HRQL, egenvårdsförmåga, känsla av sammanhang, smärta, sömn eller trötthet mellan experimentgruppen och kontrollgruppen. Deltagarna i experimentgruppen uppgav att de hade genomfört en förändring av sin livsstil som de inte hade gjort utan sitt deltagande i VVV-programmet. Exempel på livsstilsförändringar var att: försöka tänka mer positivt, tänka mer på sig själv, vara mer fysiskt aktiv, ändra på sovvanor, ändra på matvanor, minska användningen av läkemedel, och trappa ned på rökningen.

Övergripande förståelse
I det kliniska arbetet möter hälso- och sjukvårdspersonal ofta personer med långvarig muskuloskeletal smärta eller personer med reumatiska sjukdomar som frågar hur de skall kunna lindra sin smärta, sömnstörningar eller trötthet. Personer med dessa sjukdomar erbjuds då ofta läkemedel och fysisk träning som behandling. Resultatet i denna avhandling visar att hälsofrämjande faktorer som att känna sig utvilad, ha en bra sömn, ha känslomässigt stöd, ha någon grad av arbetsförmåga och att uppleva en känsla av sammanhang, bör uppmärksammas på minst samma nivå som fysisk träning inom reumatologisk vård. Som hälso- och sjukvårdspersonal är det möjligt att arbeta med att hjälpa personer med att uppnå hälsofrämjande faktorer som att känna sig utvilad, ha en god sömn, få känslomässigt stöd och någon grad av arbetsförmåga. En kontroversiell fråga är om det är möjligt att påverka känslan av sammanhang, men ett steg i rätt riktning kan vara att hälso- och sjukvårdspersonalen antar ett mer salutogenetiskt synsätt istället för det mer vanliga patogena synsätt. Om personerna får hjälp att uppleva till exempel trötthet och sömnstörningar som mer begripliga och hanterbara, och hitta en mening med att hantera dessa problem så har personerna större möjligheter att uppnå starkare känsla av sammanhang och vågar prova faktorer som kan främja deras hälsa. Att som hälso- och sjukvårdspersonal stödja till denna egenmakt (empowerment) innebär att hjälpa personerna till att lära sig att reflektera sina erfarenheter, tänka kritiskt och fatta välgrundade beslut. Denna självreflektion leder till ökad medvetenhet och förståelse för konsekvenserna av sina beslut om egenvård. När personer med reumatiska sjukdomar sedan fattar beslut om

**Slutsats**

Resultaten från denna avhandling bekräftar befintlig kunskap samtidigt som ny värdefull kunskap erhålls om hälsorådgivande faktorer hos personer med långvarig muskuloskeletal smärta eller med reumatiska sjukdomar. Det bekräftas även att egenvård upplevs som mycket mer än fysisk träning för personer med reumatiska sjukdomar. I det kliniska arbetet är det viktigt att
anta ett bredare och mer öppen syn på vad hälsofaktorer men även egenvård kan innebära för varje enskild individ. Ett försök till att finna strategier och behandlingar till förbättrad hälsa görs i denna avhandling genom att studera effekterna av ett ettårigt egenvårdsfrämjande PBL-program. Ytterligare studier behövs dock för att utveckla PBL men även andra pedagogiska modeller inom patientundervisning, för att kunna finna det bästa sättet att använda dessa modeller men framför allt för att finna belägg på långsiktiga fördelar med patientundervisning inom reumatologisk vård.

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References


Health predicting factors in a general population over an eight-year period in subjects with and without chronic musculoskeletal pain

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Abstract

Background: Many factors are proposed to be associated with health-related quality of life. Knowledge of health factors associated to development of a good health-related quality of life could be of use in clinical practice and public health work. The aim of this study was to investigate the associations between suggested health factors and health-related quality of life at baseline and in an eight-year follow up in subjects with and without chronic musculoskeletal pain in a cohort from a general population.

Methods: The study was designed as a longitudinal study in a Swedish general population (N = 1849) with a postal questionnaire at baseline 1995 and at follow up 2003. Subjects were divided into two groups, according to their response about chronic musculoskeletal pain at baseline. Health-related quality of life was assessed by the SF-36 together with suggested health factors. The associations between SF-36 subscales and suggested health factors were estimated by OR and 95% CI calculated by multivariable logistic regressions, with adjustment for all health factors, age, sex and baseline SF-36 values.

Results: Although subjects without chronic musculoskeletal pain reported better health-related quality of life than subjects with chronic pain, similar health factors were found to be associated to higher scores in SF-36 at baseline and predicted a better outcome in the eight-year follow up. The most consistent finding was a better health outcome in the eight-year follow up for subjects that were feeling rested after sleep. Other factors that in some aspects predicted a better outcome were belonging to higher socioeconomic group, being a native Swede, having emotional support, having good sleep structure, never being or being a former smoker, and regularly drinking alcohol.

Conclusion: The most important health factor in subjects with and without chronic musculoskeletal pain was feeling rested after sleep, but also emotional support, sleep structure, smoking and alcoholic habits appears to be important components. These health factors could be important to address in clinical work with painful musculoskeletal disorders. Since several health factors are common in both subjects with and without pain there could be a common strategy to be formed in public health programmes.
Background
There is an interest in health care and public health work to identify different risk factors related to disease or ill health in order to optimise prevention and early detection of health problems and poor quality of life [1]. Knowledge of risk factors as well as changes of attitude and life style in the population is supposed to prevent or reduce the burden of disease [2,3]. There has been a focus on prevention and identification of disorders with high mortality, which misses the burden of common diseases, such as musculoskeletal disorders [4,5]. Also in studies of musculoskeletal disorders and health-related quality of life [6,7], the priority has primarily been on risk factors (pathogenesis) instead of the patients' own capacity to adopt factors that promote their health (salutogenesis) [2,3]. Studies primarily looking at risk factors conclude that health could be promoted by several factors, like having a good social network and support, and good work environment [8]. Physical activity is also important [9,10], together with having a good diet [10], normal-weight [11] and being satisfied with sleep [12]. It is also important to reduce the use of alcohol [13] and tobacco [14,15].

Musculoskeletal disorders are major causes to morbidity in the world, and these conditions have a strong negative influence in terms of health-related quality of life [16]. In Europe chronic musculoskeletal pain of moderate or severe intensity occurs in 19% of the adults and these conditions limits the daily activities to a high degree [17]. Musculoskeletal pain is a public health problem and a common cause for people to seek for health care [18-20]. People with musculoskeletal pain, seeking for medical help, estimate their quality of life lower than those who do not seek for medical help [5]. It has also been shown that people with musculoskeletal pain estimates their health-related quality of life very low compared to a pain free population, and that the perceived health can predict musculoskeletal pain outcome [6,7,21].

In order to early identify and reduce the impact on health-related quality of life from musculoskeletal disorders, there is a need for more knowledge regarding factors associated to a good outcome in health. This is of interest both when meeting the patient in the clinical situation and in the public health work aiming to prevent or reduce the impact of musculoskeletal disorders in the population. Many factors are proposed to be associated with the development of health-related quality of life [8-15]. It is, from both health promotional and clinical views, of interest to study if there are different patterns of health factors in subjects with and without a chronic condition, such as chronic musculoskeletal pain. Knowledge of factors predicting good health outcome could be used to optimise treatment strategies and health factors common for subjects with and without a musculoskeletal pain could be put forward in a more general health promotion programme. There is a lack of longitudinal studies on health-related quality of life in subjects with or without chronic musculoskeletal pain, focusing on factors that predict health-related quality of life instead of risk factors. The aim of this study was to investigate the associations between suggested health factors and health-related quality of life at baseline and in an eight-year follow up in subjects with and without chronic musculoskeletal pain in a cohort from a general population.

Methods
Study design
The study was designed as a longitudinal study in a general population with postal surveys at baseline and at an eight-year follow up, and was a part of the Epipain project [22].

Subjects and data collection
The target population was all 70 704 inhabitants aged 20–74 years in two municipalities on the west coast of Sweden. In 1995 a sample of 3 928 subjects, representative for the target population, was selected from the official computerised population register. There were 2 425 subjects (62%) who, after two postal reminders, gave their written consent to participation and responded to the initial questionnaire, and 2 332 of those who responded were sent the follow up questionnaire in 2003. Ninety-three subjects were either deceased or had moved abroad. Out of the 2 332 eligible subjects, and after two postal reminders, there were 1 849 respondents (79%) at the follow up.

The 1 849 subjects were divided into two groups, according to their response about chronic musculoskeletal pain. At baseline there were 1 109 (60%) subjects without chronic pain and 700 (38%) subjects with chronic pain. There were missing data about pain for 40 (2%) subjects.

The Epipain questionnaire
The first part of the questionnaire used in the postal surveys consisted of the well-established Short Form-36 Health Survey (SF-36) in its Swedish standard version [23]. The Swedish version of SF-36 has been found to be reliable and valid [24-26]. The SF-36 is a 36 item questionnaire that gives eight subscales assessing different aspects of health-related quality of life: Physical Functioning (PF), Role – Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role – Emotional (RE) and Mental Health (MH). The score for each of the eight subscales range from 0–100. A higher score indicates better health in that aspect [23].

In the second part of the Epipain questionnaire [22], a majority of the questions were taken from prior studies, where the questions had been found useful. The face and content validity have been found to be good in the second part of the Epipain questionnaire. The reliability was
tested with a test-retest and the kappa-value was found to be ranged from 0.8 to 1.0 on the individual questions [27]. The second part of the questionnaire had an overall key question on chronic musculoskeletal pain experience: Have you experienced pain lasting more than three months during the last twelve months? It was explained in an introduction that the pain should be persistent or regularly recurrent in the musculoskeletal system. The questionnaire also assessed factors that have been proposed by previous studies to influence the effect on health-related quality of life, such as socioeconomic status, being immigrant, emotional support, regular exercise, quality of sleep, smoking and alcohol habits [8-10,13-15,22]. Socioeconomic status was based on an open question regarding the subject’s occupation. Immigrant status was based on a question regarding if the subjects themselves or at least one of their parents were born in another country. Emotional support was based on a question regarding if the subjects have one or more persons who support them to cope with distress and problems in life. Regularly exercise was based on a question regarding if the subjects exercise regularly during the week [22]. Quality of sleep was based on four questions regarding different aspects of sleep disturbances [22,28,29]. Smoking habits were based on a question regarding if the subjects were smokers or not. Alcohol habits were based on a question regarding how often the subjects were drinking alcohol [22].

### Statistical procedure and analyses

The subjects were divided into two groups, according to their response about chronic musculoskeletal pain at baseline. Subjects that could not be classified were excluded from the analyses. The actual number of subjects was based on an open question regarding the subject’s occupation. Immigrant status was based on a question regarding if the subjects themselves or at least one of their parents were born in another country. Emotional support was based on a question regarding if the subjects have one or more persons who support them to cope with distress and problems in life. Regularly exercise was based on a question regarding if the subjects exercise regularly during the week [22]. Quality of sleep was based on four questions regarding different aspects of sleep disturbances [22,28,29]. Smoking habits were based on a question regarding if the subjects were smokers or not. Alcohol habits were based on a question regarding how often the subjects were drinking alcohol [22].

The statistical analyses were done with the statistical package SPSS for Windows, release 15.0. T-test was used for statistical comparison of means. Chi-square-test was used for comparisons of prevalence between groups. The associations between the dependent variables (SF-36 subscales) and independent variables (i.e. the suggested health factors; socioeconomic status, immigrant status, emotional support, regularly exercise, sleep structure, feeling rested, smoking and alcohol habits) were estimated by odds ratios and their 95% confidence intervals calculated by multivariable logistic regressions, with adjustment for all health factors, age, sex and baseline SF-36 values. The SF-36 scores were dichotomised with regard to the mean values in the population for each subscale (1 ≥ mean and 0 < mean). The analyses were done with simple contrast to a reference group for each of the independent variables. At baseline the analyses were checked for interaction between sex or age and all of the independent variables. Subjects with missing values for any of the variables were rejected from the analyses. The actual number of subjects in each analysis is reported in Additional files 1 and 2 (Tables 1–4), and was considered to fulfill the requirement of at least 10 subjects in the outcome for each independent variable. A P-value of less than 0.05 was considered statistically significant.

### Ethics

The study was approved by the Ethics Research Committee, Faculty of Medicine, Lund University, Sweden. The Swedish Data Inspection Board approved the computerised registration.

### Results

There was a predominance of women (61% women vs. 39% men; P < 0.001) at baseline in subjects with chronic musculoskeletal pain, and a small statistically significant difference for subjects without chronic pain (52% women vs. 48% men; P < 0.001). Subjects with chronic pain were significantly older than those without chronic pain (mean age 50.3 vs. 44.6; P < 0.001). Details regarding the distribution of sociodemographic characteristics and suggested health factors with regard to the two groups with and without chronic musculoskeletal pain are found in Additional file 1 (Table 5).
Health-related quality of life at baseline and at the eight-year follow up

Subjects without chronic musculoskeletal pain scored significantly ($P < 0.001$) better than subjects with chronic musculoskeletal pain in all eight SF-36 dimensions both at baseline and at the eight-year follow up (Figure 1). The scores for all SF-36 dimensions significantly ($P < 0.001$) deteriorated over the eight-year follow up for subjects without chronic pain. The changes were more complex for subjects with chronic pain; significant worsening for PF ($P < 0.001$), SF ($P = 0.004$) and RE ($P = 0.001$), significant improvement for BP ($P = 0.004$), and no significant changes for RP ($P = 0.368$), GH ($P = 0.419$), VT ($P = 0.391$), and MH ($P = 0.633$).

Factors predicting health-related quality of life at baseline and at the eight-year follow up

The association between suggested health factors and baseline SF-36 mean scores, and the predictive value of these health factors with regard to SF-36 development over eight years, were estimated with multivariable logistic regression analyses, controlling for sociodemographic characteristics. Results from the multivariable logistic regressions with odds ratios (OR) and 95% confidence intervals (CI) for these variables are found in Additional files 1 and 2 (Tables 1–4).

For subjects without chronic musculoskeletal pain at baseline, male sex was significantly ($P < 0.05$) associated with having a health status better than the mean score at baseline in PF, VT, SF, RE, and MH, and a worse score in RP. For those with chronic musculoskeletal pain, male sex was significantly associated with having a health status better than the mean score in PF. In the eight-year follow up, male sex significantly predicted a better score only in SF for subjects with chronic pain.

For subjects without chronic musculoskeletal pain at baseline, younger age was significantly ($P < 0.05$) associated with having a health status better than the mean...
For subjects without chronic musculoskeletal pain at baseline, younger age was significantly associated with having a health status better than the mean score in PF, RP, BP and GH. For those with chronic musculoskeletal pain at baseline, belonging to a higher socioeconomic status was significantly (P < 0.05) associated with having a health status better than the mean score in PF. For those with chronic musculoskeletal pain, belonging to a higher socioeconomic status was significantly associated with having a health status better than the mean score in PF, RP, and GH. In the eight-year follow up, a higher socioeconomic status significantly predicted a better outcome in PF for subjects with chronic pain.

For subjects without chronic musculoskeletal pain at baseline, regarding immigrant status, being a native Swede was significantly (P < 0.05) associated with having a health status better than the mean score in PF, RP, GH, VT, and MH. For those with chronic musculoskeletal pain, being a native Swede was significantly associated with having a health status better than the mean score in GH and VT. In the eight-year follow up, being a native Swede significantly predicted a better outcome in RE and MH both for subjects with and without chronic pain.

For subjects without chronic musculoskeletal pain at baseline, having emotional support was significantly (P < 0.05) associated with having a health status better than the mean score in RP, GH, VT, SF, RE, and MH. For those with chronic musculoskeletal pain at baseline, emotional support was significantly associated with having a health status better than the mean score in GH, VT, SF, RE, and MH. In the eight-year follow up, emotional support significantly predicted a better outcome in RP, VT, RE, and MH in subjects with chronic pain, but was not significantly predictive in subjects without chronic pain.

For subjects without chronic musculoskeletal pain at baseline, exercise regularly was significantly (P < 0.05) associated with having a health status better than the mean score in PF, BP, and VT. For those with chronic musculoskeletal pain at baseline, exercise regularly was not significantly associated to any of the eight SF-36 health concepts. In the eight-year follow up exercise regularly failed to significantly predict any outcome in SF-36.

For subjects without chronic musculoskeletal pain at baseline, a good sleep structure was significantly (P < 0.05) associated with having a health status better than the mean score in all eight SF-36 health concepts except RP.

For subjects with chronic musculoskeletal pain at baseline, a good sleep structure was significantly associated with having a health status better than the mean score in all eight SF-36 health concepts. In the eight-year follow up a good sleep structure significantly predicted a better outcome in PF, RP, and BP for subjects without chronic pain, and in GH and RE for subjects with chronic pain.

For subjects without chronic musculoskeletal pain at baseline, feeling rested after sleep was significantly (P < 0.05) associated with having a health status better than the mean score in all eight SF-36 health concepts except BP. For those with chronic musculoskeletal pain at baseline, feeling rested was significantly associated with having a health status better than the mean score in all eight SF-36 health concepts except PF. In the eight-year follow up feeling rested significantly predicted a better outcome in BP, GH, VT, SF, RE, and MH for subjects without chronic pain, and in BP, VT, SF, RE, and MH for subjects with chronic pain.

For subjects without chronic musculoskeletal pain at baseline, and regarding smoking habits, never being a smoker or being a former smoker, compared to being a current smoker, was significantly (P < 0.05) associated with having a health status better than the mean score in PF and MH. For those with chronic musculoskeletal pain at baseline, never being a smoker or being a former smoker was not significantly associated to any outcome in SF-36. In the eight-year follow up, never being a smoker or being a former smoker significantly predicted a better outcome in GH, SF, and RE for subjects without chronic pain, and in RE and MH for subjects with chronic pain.

For subjects without chronic musculoskeletal pain at baseline, and regarding alcohol habits, drinking weekly, compared to never or rarely, was significantly (P < 0.05) associated with having a health status better than the mean score in PF, RP, and GH. For those with chronic musculoskeletal pain at baseline, weekly drinking of alcohol was significantly associated with having a health status better than the mean score in BP and VT. In the eight-year follow up weekly drinking of alcohol significantly predicted a better outcome in RP and MH for subjects without chronic pain, and in PF, RP, BP, and RE for subjects with chronic pain.

Although the multivariable logistic regression analyses were not intended to be complete explanatory models, at baseline 8.2–32.7% (Nagelkerke R²) of the variance in the dependent variables could be explained by the predictor variables for subjects without chronic pain. The figures were between 16.4–30.9% for subjects with chronic pain. In the eight-year follow up it was 14.5–40.9% for subjects without chronic pain and 26.3–49.5% for subjects with chronic pain.
**Interactions**

The analyses where checked for interactions between sex and age, and the suggested health factors at baseline. Although some interactions were noted, few were statistically significant, they were mostly inconsistent and not affecting the main outcome. For subjects with chronic musculoskeletal pain an analysis stratified on sex showed that being a native Swede was associated to better health outcome regarding RP in women but not in men (women: OR 2.95, 95% CI 1.40–6.23; men: OR 0.52, 95% CI 0.20–1.31). The same was noted for RE (women: OR 2.14, 95% CI 1.10–4.15; men: OR 0.52, 95% CI 0.17–1.53). Analyses on subjects with chronic musculoskeletal pain also showed a significant interaction between sex and former smokers in RP (women: OR 2.01, 95% CI 1.05–3.82; men: OR 0.84, 95% CI 0.39–1.82.).

Exercise regularly in age stratified analyses were shown to predict a positive outcome in all eight SF-36 domains for those in the oldest age group but not in the younger age groups for subjects with chronic pain.

**Discussion**

Although subjects without chronic musculoskeletal pain reported better health-related quality of life as measured by SF-36 than subjects with chronic musculoskeletal pain, similar health factors were found to be associated to a higher score in health at baseline and also predicted a better outcome in an eight year follow up both in subjects without and with chronic pain. The most consistent finding was a better health outcome for subjects that at baseline were _feeling rested_ after sleep. Other factors that in some aspects predicted a better outcome, controlled for age and sex, were belonging to a higher socioeconomic group, being a native Swede, having emotional support, having a good sleep structure, never being or being a former smoker, and regularly drinking alcohol.

Sociodemographic characteristics like being of male sex, younger ages, belonging to a higher socioeconomic status and being a native Swede were associated with having a health status better than the mean score in many of SF-36 health concept at baseline for both subjects with and without chronic musculoskeletal pain. It could be noted that belonging to a younger age group was associated with having a better health status at baseline in the more physical domains of SF-36 (PF, RP, BP, and GH), but not in the more mental (VT, SF, RE, and MH) domains. The same pattern could be seen in the eight year follow up. At the follow up the sociodemographic characteristics, except being of younger age, were of less importance. A study from Texas also showed that being of younger age was important when subjects estimated health but also higher income [10]. The interaction analyses in the present study showed that there could be a sex difference, especially with respect to immigrant status, where being a native Swede was a health factor for women, but not for men. A study from Canada also showed that native-born females reported better health status than foreign-born females [31].

Emotional support was found to be important for a better health-related quality of life at baseline, but at the follow up emotional support was important only for subjects with chronic musculoskeletal pain. Others have reported that emotional support could be very important for the possibilities to handle a disease such as rheumatoid arthritis and its consequences [32]. This strengthens that emotional support could be an important domain to work with in health promoting work.

It was surprising to notice that exercise regularly not was found to be important for health-related quality of life. This is not in accordance with previous studies that have shown a positive association between exercise and health [9,10]. One explanation could be how the term exercise is perceived in different age groups. It is not unlikely that the younger subjects in the present study misunderstood the question and did not count physical activity like walking as exercise. The interaction analyses could be an indicator of this, as physical exercise in age stratified analyses was shown to predict a positive outcome in most SF-36 domains for those in the oldest age group but not in the younger age groups for subjects with chronic pain. Future studies have to take this into consideration and questions may have to be more precise regarding level of physical activity. There could also be complex interactions between exercise and a number of other factors that reduce the impact of exercise in this study, which includes several other health predicting variables in the analyses.

In this study having a good sleep structure was associated to a higher score in health-related quality of life both in subjects with and without chronic musculoskeletal pain at baseline, and also predicted a better outcome over eight years in several SF-36 domains. In another study insufficient sleep also has been associated with impairment of health-related quality of life but also with frequent pain [12]. Our study indicates together with findings in other studies [33,34] that a good sleep structure could be an important domain to work with in health promoting work.

Feeling rested after sleep was the most important of the studied health factors, predicting a better outcome in most of the SF-36 dimensions for both subjects with and without chronic musculoskeletal pain at both baseline and follow up. Earlier studies have shown that tiredness and fatigue are very common symptoms in people with different diseases, for example rheumatoid arthritis and...
cancer [35,36]. But in this study we also could show that feeling rested was important even in subjects without chronic musculoskeletal pain and how they reported their health-related quality of life. The consistent finding of feeling rested as an important health factor highlight that this has to be taken into account both in care of patients and in all health promoting work.

In this study, especially at the follow up, never being a smoker or being a former smoker, compared to being current smokers, was associated to a better health-related quality of life both in subjects with and without chronic musculoskeletal pain. It has also been reported by others that those who never have smoked or were former smokers have smaller impairment on the health-related quality of life compared with subjects who were current smokers [14]. In Australia, they have found that female smokers estimated their health-related quality of life lower than female non-smokers and men smokers [15]. This is interesting with regard to the findings in this study with interaction analyses on sex, where former smoking was associated to better score in baseline SF-36 domains RP and RE in females, but not in men. This could indicate a sex difference that has to be considered in future studies.

Drinking alcohol weekly was significantly associated with having a better health status for both subjects with and without chronic musculoskeletal pain at baseline and at follow up. One earlier study has shown that people that rate their health status low was drinking alcohol more often than people with good health status [13]. Another study presented that men with frequent sleep insufficiency drink alcohol heavily [12]. In our study the quantity of alcohol was not recorded and any comparable conclusions can not be drawn. Thus, further studies have to be done with more questions about the alcohol habits and its importance for the health-related quality of life.

The factors associated to good health presented in this study could be important to address in clinical work with patients having painful musculoskeletal disorders, in order to enhance the effect of medical treatment for the disease. Since several factors are common in subjects with and without chronic musculoskeletal pain a common strategy could be formed in public health programmes on national and international levels [37].

Since SF-36 is a generic measure of health status the outcome over eight years could be expected to be influenced by a large number of factors, including the development of chronic musculoskeletal pain. In the design of the study it was decided to study two cohorts based on the baseline pain report and not to include the change in pain status in the forming of the groups. The forming of multiple groups, based on pain progression, was considered to give at too complex picture. Changes in pain status could though, together with other concomitant disorders, explain changes in health. Since predictors of pain development have been reported in several studies [6,7], it was decided not to study the progression of musculoskeletal pain, but to focus on health status as outcome in this study.

Possible confounders, bias and misclassifications
In an analysis of non-responders in a prior work of this population, it was found that people with chronic musculoskeletal pain were more prone to respond than people without musculoskeletal pain, giving a higher estimate of the prevalence [22]. This is not likely to bias the results in the follow up of the cohorts that were established in 1995.

The material was thoroughly checked for errors and subjects that could not be classified to have pain or not, were excluded from the analyses.

In our study we were not searching for the optimal model of health factors predicting health-related quality of life, therefore goodness-of-fit statistics were not tested and reported.

As age and sex were likely to be confounders we controlled for these factors in the analyses. We also controlled the baseline value for every subscale in SF-36 at the follow up to adjust for the possibility that outcome would reflect the baseline score and not a change over time. There is a problem in the use of SF-36 that floor and roof effects can reduce the possible change over time in the extreme ends of the scales.

Conclusion
The most important health factor for both subjects with and without chronic musculoskeletal pain was the report of feeling rested after sleep, associated both to a better score in most of the SF-36 dimension at baseline and predicting a better outcome at the eight-year follow up. Other health factors predicting better health-related quality of life were having emotional support, having a good sleep structure, never being or being a former smoker and regularly drinking alcohol for both subjects with and without chronic pain. These health promoting factors could be important to address in clinical work with patients having painful musculoskeletal disorders. Since several health factors are common in subjects with and without chronic musculoskeletal pain, there could be a common strategy to be formed in public health programmes on national and international levels.

Competing interests
The authors declare that they have no competing interests.
Additional material

Additional file 1
Table 1–2. Factors believed to affect health-related quality of life in a general population at baseline 1995. Odds ratios (95% CI) in multivariable analyses of factors believed to affect health-related quality of life (assessed by SF-36) in a positive way in a general population with and without chronic musculoskeletal pain at baseline 1995. Click here for file [http://www.biomedcentral.com/content/supplementary/1477-7525-6-98-S1.doc]

Additional file 2
Table 3–4. Baseline factors believed to affect health-related quality of life in a general population eight years later. Odds ratios (95% CI) in multivariable analyses of baseline factors believed to affect health-related quality of life (assessed by SF-36) in a positive way in a general population with and without chronic musculoskeletal pain eight years later. Click here for file [http://www.biomedcentral.com/content/supplementary/1477-7525-6-98-S2.doc]

Additional file 3
Table 5. Sociodemographic and supposed health-factors. Sociodemographic and supposed health-factors among a general population with and without chronic pain in 1995. Click here for file [http://www.biomedcentral.com/content/supplementary/1477-7525-6-98-S3.doc]

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References


Table 1. Factors believed to affect health-related quality of life in a general population at baseline 1995

Odds ratios (95% CI) in multivariable analyses of factors believed to affect health-related quality of life (assessed by SF-36) in a positive way in a general population with and without chronic musculoskeletal pain at baseline 1995

<table>
<thead>
<tr>
<th>Physical function (PF)</th>
<th>Role-Physical (RP)</th>
<th>Bodily pain (BP)</th>
<th>General health (GH)</th>
</tr>
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<tbody>
<tr>
<td>Without pain</td>
<td>With pain</td>
<td>Without pain</td>
<td>With pain</td>
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<tr>
<td>n= 1018</td>
<td>n= 639</td>
<td>n= 1014</td>
<td>n= 640</td>
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<tr>
<th>OR (95% CI)</th>
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</table>

| Sex | Women | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|     | Men   | 1.8 (1.2-2.8) | 1.8 (1.2-2.6) | 0.7 (0.5-0.9) | 1.0 (0.7-1.5) | 1.0 (0.7-1.4) | 1.2 (0.7-1.8) | 1.0 (0.7-1.4) | 0.9 (0.6-1.3) |

| Age | 59-74 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|     | 47-58 | 4.0 (2.4-6.7) | 2.2 (1.3-3.7) | 2.4 (1.4-4.1) | 1.9 (1.2-3.0) | 1.3 (0.8-2.2) | 2.0 (1.1-3.6) | 2.5 (1.5-4.0) | 3.9 (2.3-6.6) |
|     | 34-46 | 9.4 (5.1-17.4) | 5.3 (3.1-9.2) | 3.4 (1.9-6.0) | 2.0 (1.2-3.3) | 1.7 (1.1-2.9) | 1.8 (0.9-3.5) | 2.9 (1.8-4.7) | 3.5 (1.9-6.1) |
|     | 20-33 | 18.9 (9.4-37.9) | 8.3 (4.5-15.2) | 2.5 (1.4-4.3) | 2.8 (1.6-4.8) | 2.0 (1.2-3.4) | 2.6 (1.3-5.1) | 2.2 (1.4-3.6) | 3.9 (2.1-7.2) |

| Socio-economic status | Group A | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|                       | Group B | 0.9 (0.5-1.6) | 1.1 (0.6-2.0) | 0.9 (0.5-1.6) | 1.2 (0.7-1.9) | 1.1 (0.7-1.9) | 1.5 (0.8-2.7) | 1.3 (0.8-2.1) | 1.2 (0.7-2.1) |
|                       | Group C | 1.9 (1.1-3.3) | 2.2 (1.3-3.6) | 1.0 (0.6-1.6) | 1.8 (1.1-2.8) | 1.4 (0.9-2.2) | 1.5 (0.9-2.6) | 1.3 (0.9-1.9) | 1.7 (1.0-2.7) |
|                       | Group D | 0.8 (0.4-1.4) | 1.5 (0.8-3.0) | 0.9 (0.5-1.6) | 0.6 (0.3-1.2) | 1.0 (0.6-1.7) | 0.7 (0.3-1.7) | 1.1 (0.6-1.8) | 1.1 (0.6-2.2) |

| Immigrant status | Immigrant | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|                 | Swede    | 2.3 (1.2-4.3) | 1.3 (0.7-2.2) | 2.0 (1.1-3.6) | 1.6 (0.9-2.8) | 1.7 (0.9-2.9) | 1.1 (0.6-2.3) | 1.9 (1.1-3.2) | 2.3 (1.2-4.3) |

| Emotional support | No | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|                 | Yes | 1.3 (0.7-2.4) | 1.2 (0.7-2.0) | 2.3 (1.3-3.9) | 0.9 (0.6-1.5) | 1.0 (0.6-1.7) | 2.1 (0.9-4.3) | 2.3 (1.4-3.8) | 2.2 (1.2-3.9) |

| Exercise regularly | Yes, 1-2 times a week | 2.4 (1.5-3.9) | 0.9 (0.6-1.4) | 1.1 (0.7-1.7) | 1.2 (0.8-1.7) | 1.8 (1.2-2.7) | 1.1 (0.7-1.8) | 1.0 (0.7-1.5) | 1.1 (0.7-1.6) |
|                    | Yes, > 2 times a week | 2.4 (1.4-4.2) | 1.1 (0.7-1.9) | 0.9 (0.6-1.5) | 1.0 (0.6-1.5) | 1.1 (0.7-1.7) | 1.1 (0.6-1.9) | 1.4 (0.9-2.1) | 1.4 (0.9-2.3) |

| Sleep structure | Bad | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|                | Good | 1.7 (1.1-2.7) | 2.5 (1.7-3.9) | 1.4 (0.9-2.2) | 1.9 (1.3-2.8) | 1.7 (1.1-2.5) | 2.5 (1.5-4.1) | 2.4 (1.7-3.4) | 2.0 (1.3-3.0) |

| Feeling rested | No | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|               | Yes | 3.2 (1.9-5.2) | 1.3 (0.9-2.0) | 2.6 (1.6-4.1) | 1.5 (1.0-2.3) | 1.5 (0.9-2.4) | 1.7 (1.0-2.8) | 2.9 (2.0-4.4) | 2.7 (1.8-4.1) |

| Smoking habit | Current | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|              | Former | 1.8 (0.9-3.1) | 1.3 (0.8-2.1) | 1.1 (0.6-2.0) | 1.4 (0.9-2.2) | 1.5 (0.9-2.5) | 1.1 (0.6-2.1) | 1.0 (0.8-1.6) | 0.9 (0.5-1.5) |
|              | Never | 2.0 (1.2-3.3) | 1.5 (0.9-2.5) | 0.8 (0.5-1.3) | 1.0 (0.7-1.6) | 1.2 (0.8-1.8) | 1.3 (0.7-2.3) | 1.2 (0.8-1.9) | 0.9 (0.5-1.4) |

| Alcohol habit | Never/rare | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
|              | Monthly | 1.4 (0.9-2.3) | 1.4 (0.9-2.2) | 1.2 (0.8-1.8) | 1.0 (0.7-1.5) | 1.0 (0.7-1.5) | 1.4 (0.8-2.3) | 1.6 (1.1-2.4) | 0.8 (0.5-1.3) |
|              | Weekly | 2.0 (1.1-3.5) | 1.6 (0.9-2.6) | 2.4 (1.4-4.3) | 1.3 (0.8-2.2) | 1.5 (0.9-2.4) | 1.9 (1.1-3.6) | 1.7 (1.1-2.6) | 1.3 (0.7-2.1) |

Group A: Manual workers
Group B: Assistant no manual employees
Group C: Intermediate/higher employees and upper-level executives
Group D: Others
Table 2. Factors believed to affect health-related quality of life in the general population at baseline 1995

<table>
<thead>
<tr>
<th>Vitality (VT)</th>
<th>Social Functioning (SF)</th>
<th>Role-Emotional (RE)</th>
<th>Mental Health (MH)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
</tr>
<tr>
<td>n= 1027</td>
<td>n= 645</td>
<td>n= 1034</td>
<td>n= 657</td>
</tr>
<tr>
<td>Sex</td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>OR (95% CI)</td>
<td>1.4 (1.0-2.0)</td>
<td>1.0 (0.7-1.6)</td>
<td>1.8 (1.2-2.5)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>59-74</td>
<td>47-58</td>
<td>34-46</td>
</tr>
<tr>
<td>OR (95% CI)</td>
<td>1.6 (0.9-2.7)</td>
<td>1.4 (0.8-2.2)</td>
<td>0.6 (0.4-1.1)</td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>Group A</td>
<td>Group B</td>
<td>Group C</td>
</tr>
<tr>
<td>OR (95% CI)</td>
<td>1.5 (0.9-2.6)</td>
<td>0.8 (0.5-1.5)</td>
<td>1.5 (0.9-2.7)</td>
</tr>
<tr>
<td>Immigrant status</td>
<td>Swede</td>
<td>Immigrant</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Yes</td>
<td>No</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Regularly</td>
<td>No</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Sleep</td>
<td>Good</td>
<td>Bad</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Smoking habit</td>
<td>Current</td>
<td>Former</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Alcohol habit</td>
<td>Never</td>
<td>Monthly</td>
<td>Weekly</td>
</tr>
</tbody>
</table>

**Note:** OR = Odds Ratio; 95% CI = 95% Confidence Interval; VT = Vitality; SF = Social Functioning; RE = Role-Emotional; MH = Mental Health.
### Table 3. Baseline factors believed to affect health-related quality of life in a general population eight years later

<table>
<thead>
<tr>
<th>Physical function (PF)</th>
<th>Role-Physical (RP)</th>
<th>Bodily pain (BP)</th>
<th>General health (GH)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
</tr>
<tr>
<td>n= 1011</td>
<td>n= 634</td>
<td>n= 1004</td>
<td>n= 1029</td>
</tr>
<tr>
<td>OR (95 % CI)</td>
<td>OR (95 % CI)</td>
<td>OR (95 % CI)</td>
<td>OR (95 % CI)</td>
</tr>
<tr>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
</tr>
<tr>
<td>n= 1004</td>
<td>n= 615</td>
<td>n= 1005</td>
<td>n= 631</td>
</tr>
<tr>
<td>OR (95 % CI)</td>
<td>OR (95 % CI)</td>
<td>OR (95 % CI)</td>
<td>OR (95 % CI)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Men 1.3 (0.8-1.9)</td>
<td>1.2 (0.8-1.4)</td>
<td>1.2 (0.9-1.7)</td>
<td>1.1 (0.7-1.6)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>59-74 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>47-58 3.6 (2.2-6.1)</td>
<td>3.4 (1.9-5.9)</td>
<td>2.9 (1.8-4.6)</td>
<td>1.4 (0.9-2.3)</td>
</tr>
<tr>
<td>34-46 6.3 (3.5-11.2)</td>
<td>6.5 (3.4-12.1)</td>
<td>3.1 (1.9-5.0)</td>
<td>3.0 (1.8-5.2)</td>
</tr>
<tr>
<td>20-33 10.3 (5.4-19.4)</td>
<td>9.4 (4.6-19.1)</td>
<td>3.6 (2.2-5.8)</td>
<td>2.2 (1.2-3.9)</td>
</tr>
<tr>
<td><strong>Socio-economic status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group A 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Group B 1.1 (0.6-2.0)</td>
<td>1.1 (0.6-2.0)</td>
<td>0.8 (0.5-1.3)</td>
<td>0.7 (0.4-1.3)</td>
</tr>
<tr>
<td>Group C 1.4 (0.9-2.3)</td>
<td>2.0 (1.2-3.5)</td>
<td>1.3 (0.9-2.0)</td>
<td>1.0 (0.6-1.7)</td>
</tr>
<tr>
<td>Group D 0.8 (0.4-1.6)</td>
<td>1.2 (0.6-2.6)</td>
<td>0.8 (0.5-1.3)</td>
<td>0.9 (0.5-1.7)</td>
</tr>
<tr>
<td><strong>Immigrant status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immigrant 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Swede 1.5 (0.7-2.9)</td>
<td>1.2 (0.6-2.3)</td>
<td>1.4 (0.8-2.4)</td>
<td>1.5 (0.8-2.7)</td>
</tr>
<tr>
<td><strong>Emotional support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Yes 0.8 (0.4-1.5)</td>
<td>1.0 (0.5-1.7)</td>
<td>1.6 (0.9-2.6)</td>
<td>1.7 (1.0-2.8)</td>
</tr>
<tr>
<td><strong>Exercise regularly</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, 1-2 times a week 1.0 (0.6-1.6)</td>
<td>0.9 (0.6-1.5)</td>
<td>1.1 (0.7-1.5)</td>
<td>1.1 (0.7-1.7)</td>
</tr>
<tr>
<td>Yes, &gt; 2 times a week 1.0 (0.6-1.7)</td>
<td>0.7 (0.4-1.2)</td>
<td>0.9 (0.6-1.4)</td>
<td>1.1 (0.8-1.7)</td>
</tr>
<tr>
<td><strong>Sleep structure</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bad 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Good 1.7 (1.0-2.6)</td>
<td>0.7 (0.4-1.2)</td>
<td>1.7 (1.2-2.5)</td>
<td>1.5 (0.9-2.3)</td>
</tr>
<tr>
<td><strong>Feeling rested</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Yes 1.2 (0.7-2.1)</td>
<td>1.5 (0.9-2.4)</td>
<td>1.3 (0.9-2.1)</td>
<td>1.9 (1.3-2.9)</td>
</tr>
<tr>
<td><strong>Smoking habit</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Former 1.3 (0.7-2.4)</td>
<td>0.9 (0.5-1.6)</td>
<td>1.5 (0.9-2.4)</td>
<td>0.8 (0.5-1.4)</td>
</tr>
<tr>
<td>Never 1.1 (0.6-1.8)</td>
<td>1.5 (0.9-2.6)</td>
<td>1.1 (0.7-1.6)</td>
<td>1.3 (0.8-2.2)</td>
</tr>
<tr>
<td><strong>Alcohol habit</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never/rare 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Monthly 1.3 (0.8-2.0)</td>
<td>1.4 (0.9-2.3)</td>
<td>1.3 (0.9-1.8)</td>
<td>1.8 (1.1-2.7)</td>
</tr>
<tr>
<td>Weekly 1.6 (0.9-2.9)</td>
<td>2.7 (1.5-4.8)</td>
<td>1.7 (1.0-2.7)</td>
<td>2.1 (1.2-3.5)</td>
</tr>
<tr>
<td><strong>SF-36 at baseline</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥mean 1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>&lt;mean 8.8 (5.5-14.2)</td>
<td>9.1 (5.8-14.3)</td>
<td>2.8 (1.9-4.3)</td>
<td>3.8 (2.6-5.5)</td>
</tr>
</tbody>
</table>
Table 4. Baseline factors believed to affect health-related quality of life in a general population eight years later

<table>
<thead>
<tr>
<th>Vitality (VT)</th>
<th>Social Functioning (SF)</th>
<th>Role-Emotional (RE)</th>
<th>Mental Health (MH)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
<td><strong>Without pain</strong></td>
<td><strong>With pain</strong></td>
</tr>
<tr>
<td><strong>n=1017</strong></td>
<td><strong>OR (95% CI)</strong></td>
<td><strong>n=639</strong></td>
<td><strong>OR (95% CI)</strong></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Men</td>
<td>1.2 (0.8-1.6)</td>
<td>1.4 (0.9-2.0)</td>
<td>1.4 (0.9-1.9)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47-58</td>
<td>1.6 (0.9-2.5)</td>
<td>1.1 (0.7-1.7)</td>
<td>1.8 (1.1-2.9)</td>
</tr>
<tr>
<td>34-46</td>
<td>1.1 (0.7-1.7)</td>
<td>1.6 (0.9-2.7)</td>
<td>1.3 (0.8-2.1)</td>
</tr>
<tr>
<td>20-33</td>
<td>1.0 (0.6-1.6)</td>
<td>1.2 (0.7-2.1)</td>
<td>1.2 (0.7-1.9)</td>
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<tr>
<td><strong>Socio-economic status</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Group A</td>
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<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Group B</td>
<td>1.0 (0.6-1.7)</td>
<td>1.0 (0.6-1.7)</td>
<td>0.6 (0.4-0.9)</td>
</tr>
<tr>
<td>Group C</td>
<td>1.3 (0.9-1.8)</td>
<td>0.9 (0.6-1.5)</td>
<td>0.9 (0.6-1.3)</td>
</tr>
<tr>
<td>Group D</td>
<td>0.8 (0.5-1.3)</td>
<td>0.8 (0.4-1.4)</td>
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<td><strong>Immigrant status</strong></td>
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<td>1.00</td>
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<tr>
<td>Swede</td>
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<td>1.2 (0.7-2.3)</td>
<td>1.6 (0.9-2.6)</td>
</tr>
<tr>
<td><strong>Emotional support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Yes</td>
<td>1.3 (0.8-2.1)</td>
<td>1.7 (1.0-3.0)</td>
<td>1.6 (0.9-2.6)</td>
</tr>
<tr>
<td><strong>Exercise regularly</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Yes, 1-2 times a week</td>
<td>1.0 (0.7-1.5)</td>
<td>1.1 (0.7-1.7)</td>
<td>1.0 (0.7-1.4)</td>
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<td>1.1 (0.7-1.7)</td>
<td>0.7 (0.5-1.1)</td>
</tr>
<tr>
<td><strong>Sleep</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Bad</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Good</td>
<td>1.3 (0.9-1.8)</td>
<td>1.3 (0.8-2.0)</td>
<td>1.3 (0.9-1.9)</td>
</tr>
<tr>
<td><strong>Feeling rested</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Yes</td>
<td>2.1 (1.4-3.2)</td>
<td>1.6 (1.1-2.5)</td>
<td>1.7 (1.1-2.7)</td>
</tr>
<tr>
<td><strong>Smoking habit</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Former</td>
<td>1.4 (0.9-2.2)</td>
<td>1.1 (0.7-1.9)</td>
<td>2.1 (1.3-3.3)</td>
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<tr>
<td>Never</td>
<td>1.3 (0.9-1.9)</td>
<td>1.1 (0.7-1.7)</td>
<td>1.7 (1.2-2.6)</td>
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<tr>
<td>Alcohol habit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never/rare</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Monthly</td>
<td>1.1 (0.7-1.5)</td>
<td>1.1 (0.7-1.7)</td>
<td>1.0 (0.7-1.4)</td>
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<tr>
<td>Weekly</td>
<td>1.2 (0.8-1.9)</td>
<td>1.4 (0.8-2.3)</td>
<td>1.1 (0.7-1.8)</td>
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</tbody>
</table>

SF-36 at >mean baseline <mean

4.2 (3.0-5.9) 4.3 (2.9-6.3) 3.0 (2.1-4.4) 4.7 (3.2-6.8) 2.9 (2.0-4.4) 3.2 (2.2-4.7) 3.0 (2.1-4.2) 4.1 (2.8-5.9)

Group A: Manual workers
Group B: Assistant no manual employees
Group C: Intermediate/higher employees and upper-level executives
Group D: Others

Study I
Table 5. Sociodemographic and supposed health-factors among a general population with and without chronic pain in 1995

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Without pain</th>
<th>With pain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=1109</td>
<td>n=700</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
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</tr>
<tr>
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<td>388</td>
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</tr>
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<tr>
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<td>Good</td>
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<tr>
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<tr>
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<td>Weekly</td>
<td>281</td>
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*Statistically significant (p<0.05) difference between the two groups
Factors promoting health-related quality of life in people with rheumatic diseases: a 12 month longitudinal study

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Abstract

**Background:** Rheumatic diseases have a significant adverse impact on the individual from physical, mental and social aspects, resulting in a low health-related quality of life (HRQL). There is a lack of longitudinal studies on HRQL in people with rheumatic diseases that focus on factors promoting HRQL instead of risk factors. The aim of this study was to investigate the associations between suggested health promoting factors at baseline and outcome in HRQL at a 12 month follow-up in people with rheumatic diseases.

**Methods:** A longitudinal cohort study was conducted in 185 individuals with rheumatic diseases with questionnaires one week and 12 months after rehabilitation in a Swedish rheumatology clinic. HRQL was assessed by SF-36 together with suggested health factors. The associations between SF-36 subscales and the health factors were analysed by multivariable logistic regressions.

**Results:** Factors predicting better outcome in HRQL in one or several SF-36 subscales were being younger or middle-aged, feeling painless, having good sleep structure, feeling rested after sleep, performing low effort of exercise more than twice per week, having strong sense of coherence (SOC), emotional support and practical assistance, higher educational level and work capacity. The most important factors were having strong SOC, feeling rested after sleep, having work capacity, being younger or middle-aged, and having good sleep structure.

**Conclusions:** This study identified several factors that promoted a good outcome in HRQL to people with rheumatic diseases. These health factors could be important to address in clinical work with rheumatic diseases in order to optimise treatment strategies.
Background

Rheumatic diseases have a significant adverse impact on the individual from physical, mental and social aspects [1], resulting in a low health-related quality of life (HRQL) [2-4]. Recent research suggests that individuals with rheumatoid arthritis (RA) who receive a multi-disciplinary team-based care at a rheumatology clinic get improved HRQL and also a decrease in symptoms from the joints and in inflammatory parameters up to 12 months after an intervention [5,6]. However, little attention has been paid on studying the effect of health factors (salutogenesis) instead of risk factors (pathogenesis) within the context of rheumatic care.

The objective of a salutogenetic approach is to enhance the individual’s resources to become more resistant to the debilitating effects of the disease. The focus is on the human strengths and factors that create the conditions for health. If an individual experiences life as understandable and manageable as well as finds it meaningful in dealing with problems that arise, then this individual has a greater ability to stay healthy and to have a strong sense of coherence (SOC). The most important determinant for SOC is personal relationships and not the social environment [9, 10]. Women with fibromyalgia who had a stronger SOC perceived greater well-being, and felt more hopeful, free, valuable and more like others [11]. Older individuals with RA who have social support reported better self-care behaviour [12] and individuals with systemic lupus erythematosus (SLE) with a strong SOC had the ability to cope with disease-related stressors and get better HRQL [13]. In people with RA and osteoarthritis, exercise intervention could have a moderate positive effect on physical activity behaviour [14, 15] but does not always improve HRQL in people with RA [15]. Several other factors can be supposed to promote health in people with rheumatic diseases.

In order to optimise treatment strategies within the clinical practice it would be valuable to identify health factors that affect HRQL in a positive direction. There is a lack of longitudinal studies on HRQL in people with rheumatic diseases that focus on factors predicting HRQL instead of risk factors.

The aim of this study was to investigate the associations between suggested health promoting factors at baseline and outcome in HRQL at a 12 month follow-up in people with rheumatic diseases.

Methods

Design and setting

The study was designed as a longitudinal cohort study in people with rheumatic diseases, with a questionnaire one week and 12 months after a completed rehabilitation program in a Swedish rheumatology clinic. The individuals, aged 18 years or older and primarily from the middle and south of Sweden, had undergone an inpatient rehabilitation program which has been referred by physicians. Focus during the stay at the clinic was physical training and medical help but also to support, teach and provide individual advice for self-care.
Participants and drop outs

All individuals (n=249) with at least one diagnosed rheumatic disease who received three weeks of rehabilitation at the clinic during the period February – June 2007 and with no great difficulties to read and complete the Swedish questionnaire were asked to participate in the study. There were 200 (80 %) individuals included one week after rehabilitation and at the 12 month follow-up there were 185 (74 %) individuals who responded to the questionnaire.

At the 12 month follow-up there were 15 individuals who decided not to participate, of whom one (7 %) was a man and 14 (93 %) were women. Their mean age was 62 years (24-81 years). Nine (60 %) of the individuals were living alone and six (40 %) of the individuals were living with somebody. Seven (47 %) had grade school as highest education, five (33 %) had secondary school and three (20 %) had college/university as highest education. There were six (40 %) of the individuals who had an inflammatory joint disease, four (27 %) had a systemic rheumatic disease, two (13 %) had osteoarthritis, and three (20 %) had local/general pain. Additionally, there was a higher percentage in the group of dropouts who were women, were living alone and who had a systemic rheumatic disease compared to the individuals who completed the study (Table 1).

Data collection

A cover letter, an informed consent and a questionnaire were sent to the individuals one week after discharge from the clinic. The informed consent and, in the event that the individuals decided to participate, the completed questionnaire were returned to the first author. Three weeks after the discharge from the clinic a reminder was done by a telephone call. A similar procedure was carried out at 12 months after completed rehabilitation.

Instruments

The salutogenetic perspective was the starting point in the selection of measuring instruments and the following areas were chosen: HRQL, feeling painless, sleep structure, feeling rested, diet, exercise habits, performing hobbies, feeling sexual lust, SOC, social support, alcohol habit, immigrant status, civil status, education, work capacity, socioeconomic status – main occupation, socioeconomic status – current occupation, and rheumatic disease.

- In order to assess HRQL the Short Form-36 health survey (SF-36), a general questionnaire was used [16]. The Swedish version of SF-36 has shown good reliability and validity [17-19]. The SF-36 gives eight subscales assessing different aspects of HRQL: Physical Functioning (PF), Role – Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role – Emotional (RE) and Mental Health (MH). The score for each of the eight subscales ranged from 0 to 100. A higher score indicated better health [16].

- Feeling painless was assessed by a general question about the average pain intensity the past week and the response ranged from 0 to 10, where a lower score indicated less pain (study specific question).

- Sleep structure was assessed by three questions regarding experiences of problems falling asleep, frequent awakenings during the night and early morning awakening. A fourth question, assessing not feeling rested after sleep, represented a more qualitative aspect of non-restorative sleep and was introduced separately in the analyses as feeling rested. Sleep structure and feeling rested were assessed with five alternatives: (1) No problems; (2) Small problems; (3) Some problems; (4) Great problems; and (5) Very great problems [20-22].
Diet was assessed with six alternatives: (1) General diet; (2) Only lacto-vegetarian diet; (3) Most lacto-vegetarian diet but occasionally eat fish and egg; (4) Vegan diet; (5) Gluten-free diet; and (6) Other diet, please describe [23].

Exercise habits were assessed by three questions about the frequency of exercise on different levels of effort: high, medium and low effort. There were five alternatives: (1) Never; (2) Irregularly; (3) One time per week; (4) Two times per week; and (5) Three or more times per week [24].

Performing hobbies was assessed with four alternatives: (1) Never; (2) Rarely; (3) Sometimes; and (4) Often (study specific question).

Feeling sexual lust was assessed with four alternatives: (1) Never; (2) Rarely; (3) Sometimes; and (4) Often [25].

The SOC is a questionnaire based on Antonovsky’s salutogenic theory and was used to assess the sense of coherence, measured by comprehensibility, manageability and meaningfulness. The version with 13 questions was selected [10] since this shorter version has shown good reliability and validity [26, 27]. The score for each of the questions ranged from 1 to 7. A higher score indicated a strong SOC [27].

The Social Network and Social Support Scale (SNASS) is a questionnaire used to assess social support and shows good reliability and validity [28, 29]. The 10 questions that affect emotional support and practical assistance were included in the present study. The score for each of the 10 questions ranged from: Yes, absolutely= one point; Yes, partly=two points; and No=three points. A lower score indicated a strong emotional support and practical assistance [28, 29].

Alcohol habit assessed the frequency of alcohol use with five alternatives: (1) Never; (2) Very seldom; (3) Monthly; (4) One or two times per week; and (5) Daily [20].

Work capacity assessed the degree of the work capacity with six alternatives: (1) 100 %; (2) 75 %; (3) 50 %; (4) 25 %; (5) No work capacity; and (6) Retired (study specific question).

Socioeconomic status was based on the occupation and classified according to the Swedish socioeconomic classification system, SEI [30].

The diagnosed rheumatic disease was obtained from medical records.

A pilot study to test the questionnaire was done on 24 other individuals that varied in sex, age, and occurrence of diseases or not. Thereafter some minor adjustments were made in the layout of the questionnaire and some study specific questions were clarified to reduce the risk of misinterpretation.

**Statistical procedure and analysis**

The SF-36 outcome scores were dichotomised with regard to the mean values in the population for each of the eight subscales (1 >mean and 0 <mean). Age and feeling painless were divided into quartiles. Moderate or big problems in any of the three questions about sleep were considered as representative for problems with sleep structure. In the analyses about sleep structure and feeling rested, the answers were merged into three groups with scores 1-2 representing no/small problems, score 3 representing moderate problem, and scores 4-5 representing big/very big problems. In the analyses about diet, the answers were merged into two groups with score 1 representing general diet and scores 2-6 representing special diet. In the analyses about exercise habits, the answers from each of the three questions were merged into three groups with scores 1-2 representing never/irregularly, score 3 representing one
time per week and scores 4-5 representing >2 times per week. In the analyses about performing hobbies and feeling sexual lust, the answers to each question were merged into two groups with scores 1-2 representing never/rarely and scores 3-4 representing sometimes/often. The questions from SOC and social support were calculated and then the values were divided into quartiles. In the analyses about alcohol habit, the answers were merged into three groups with scores 1-2 representing never/rare, score 3 representing monthly, and scores 4-5 representing weekly. In the analyses about work capacity, the answers were merged into three groups with scores 1-4 representing 25-100% work capacity, score 5 representing no work capacity, and score 6 representing retired. Socioeconomic status was classified according to the Swedish socioeconomic classification system, SEI [30], and the 18 basic socioeconomic classes were merged into four groups: manual workers, assistant no manual employees, intermediate/higher no manual employees including upper level executives, and others. The group “others” included self-employed, farmers, housewives, and students [31]. The rheumatic diseases were merged into four groups: inflammatory joint disease, systemic rheumatic disease, osteoarthritis and local/general pain [32].

The statistical package SPSS for Windows, Release 17.0 was used in the analysis. The t-test was used for statistical comparison of means. The chi-square-test was used for comparisons of prevalence between groups. The associations between the dependent variable (SF-36 subscales) and independent variables (the suggested health factors; feeling painless, sleep structure, feeling rested, diet, exercise, performing hobbies, feeling sexual lust, SOC, social support, alcohol habit, immigrant status, civil status, education, work capacity, socioeconomic status – main occupation, socioeconomic status – current occupation, and rheumatic disease) were estimated by odds ratios (OR) and 95% confidence intervals (CI) calculated by multivariable logistic regressions for each of the variables at a time with adjustment for sex, age and baseline SF-36 values. The analyses were done with simple contrast to a reference group for each of the independent variables. Individuals with missing values for any of the variables were rejected from the analyses. The actual number of individuals in each analysis is reported in tables 2-3, and was considered to fulfil the requirement of at least 10 individuals in the outcome for each independent variable. A p-value of less than 0.05 was considered statistically significant. A power calculation showed that at least 150 individuals would be enough. The power calculation was based on the analysis of the SF-36 vitality scale and a power of more than 80% for a two-tailed test, a significance level of 5% and an assumption that the minimum difference between the groups was 6 points and the maximum standard deviation was 20 points [33].

Ethics
The study was approved by the Ethics Research Committee, Faculty of Medicine, Lund University, Sweden, dnr 566/2006.

Results
The most common group of rheumatic diseases was inflammatory joint diseases (63%). There was a predominance of women (75%) (Table 1), and the mean age was 59.4 years. There were significant deteriorations in seven of the SF-36 dimensions between the one week and the 12 month follow-up. The mean changes were for PF
Factors impact on HRQL at the 12 month follow-up

The predictive value of the suggested health factors with regard to SF-36 development over 12 months was estimated with multivariable logistic regression analyses, where each of the health factors was controlled for sex, age and baseline SF-36. Results from the multivariable logistic regressions with OR and 95% CI for these variables are found in tables 2-3.

Sex was not associated with having a health status better than the mean score in any of the SF-36 subscales at the 12 month follow-up. Younger age (18-51 years) significantly \((p< 0.05)\) predicted a health status better than the mean score in PF and RE compared to older age (70-88 years). Being 52-60 years significantly predicted a better outcome in PF, RP and RE compared to older age (70-88 years).

A lower score (indicating less pain) in feeling painless significantly \((p< 0.05)\) predicted a health status better than the mean score in BP at the 12 month follow-up, compared to feeling strong pain (8-10 points). Having no/small problem with the sleep structure predicted a better outcome in GH and VT, and having moderate problem with the sleep structure predicted a better outcome in VT compared to big/very big problem with the sleep structure. Feeling rested after sleep predicted a better outcome in five of the SF-36 subscales, RP, BP, GH, VT and SF, compared to reporting big/very big problem with not feeling rested. Moderate problem with feeling rested after sleep predicted a better outcome in VT compared to reporting big/very big problem with not feeling rested.

The special diet was not associated with having a health status better than the mean score in any of the SF-36 subscales at the 12 month follow-up compared to general diet. High or medium effort of exercise once per week predicted a worse outcome in SF compared to do irregularly/never effort of exercise. Low effort of exercise more than twice per week predicted a better outcome in PF compared to do irregularly/never effort of exercise. Performing hobbies or feeling sexual lust often/sometimes was not associated with having a health status better than the mean score in any of the SF-36 subscales at the 12 month follow-up compared to performing hobbies or feeling sexual lust rarely/never.

A strong/very good or a slightly weaker SOC significantly \((p< 0.05)\) predicted a health status better than the mean score in seven of the SF-36 subscales, RP, BP, GH, VT, SF, RE and MH, at the 12 month follow-up compared to a very weak SOC (21-55 points). A weaker SOC predicted a better outcome in BP, GH, VT, RE and MH compared to a very weak score. All lower and better scores of social support (emotional support and practical assistance) predicted a better outcome in RE compared to the highest and worst score (18-29 points).

The alcohol habit (weekly compared to rarely/never drink alcohol), immigrant status (Swede compared to immigrant) or civil status (living with somebody compared with living alone) were not associated with having a health status better than the mean score in any of the SF-36 subscales at the 12 month follow-up. Secondary school as highest education predicted a better outcome in SF compared to grade school.
A work capacity of 25-100 % significantly ($p < 0.05$) predicted a health status better than the mean score in PF, RP, BP and MH at the 12 month follow-up compared to 0 % work capacity. The socioeconomic status, main occupation (assistant no manual employees, intermediate/higher employees and upper-level executives, and others) did not predict any better outcome in SF-36 compared to manual workers. The socioeconomic status, current occupation and the group D (Others) predicted a worse outcome in BP and GH compared to manual workers. The rheumatic disease (inflammatory joint disease, systemic rheumatic disease and osteoarthritis) was not associated with having a health status better than the mean score in any of the SF-36 subscales at the 12 month follow-up compared to local/general pain.

The multivariate logistic regression analyses were not intended to be complete explanatory models, but at the 12 month follow-up 48.8-55.3 % of the variance in PF could be explained by the predictor variables (Nagelkerke $R^2$) and 21.2-33.5 % in RP, 14.3-25.6 % in BP, 31.1-43.9 % in GH, 16.6-26.0 % in VT, 20.3-30.1% in SF, 28.0-40.1 % in RE and 32.3-44.0 % in MH.

**Discussion**

The focus in this study was on the effect of proposed health factors on the long-term outcome in HRQL in people with rheumatic diseases that had the same starting point, they had undergone inpatient rehabilitation. The individuals had a statistically significant deterioration in SF-36 between baseline at one week and the follow-up 12 months after the rehabilitation. The health factors that proved to affect most subscales in HRQL in a positive way were having a strong SOC, feeling rested after sleep, having work capacity, being younger or middle-aged, and having no/small problem with the sleep structure.

The most obvious health factor was having strong SOC which was predicting a positive outcome in seven of the eight SF-36 subscales at the 12 month follow-up. This agreed well with the results from Abu-Shakra et al. where SOC had a major influence on the quality of life in individuals with SLE. These individuals with strong SOC had the ability to predict, explain and cope with disease related stressors and achieve a better quality of life [13]. The same results were shown in individuals with scleroderma [34]. Antonovsky meant that the SOC changed very little in adulthood, if the individual was not exposed to major changes in life like moving to another place, giving birth to a child or going into rehabilitation[10]. It has been shown that SOC is only stable for individuals with initially high scores of SOC. For individuals with lower SOC, the condition of disease and societal changes influences the score [35]. This indicates that the SOC can be affected. SOC is therefore an important domain to take into account and to study more in order to develop strategies in clinical practice.

Another important health factor in the present study was feeling rested after sleep. The same result was shown in an eight-year follow up of individuals with or without chronic musculoskeletal pain [36]. Some of the main factors that influence the quality of life negatively in individuals with RA are sleep disturbance and fatigue [37]. Fatigue is a common problem in individuals with chronic illnesses and this subjective symptom worries the individuals. Healthcare professionals have to learn communication techniques to help individuals to express concerns about fatigue [38,
More research is needed to find the best way of treating fatigue in people with rheumatic diseases.

Having work capacity was also an important health factor. This agreed well with another study where external factors like employment and having financial support were important to secure health. External factors were strongly linked to the perceptions of normality [40]. There is an association between work disability and RA. Factors that contribute to decisions to cease work are the physical nature of the work, the workload, the fatigue or the pain [41]. Conversely, the present study showed that the work capacity contributed to a higher score in health status. It is therefore important to help individuals to be able to continue to work, regardless of the number of working hours, but adjustments of the nature of the work and workload have to be made.

Age was also an important health factor in this study. Being of younger age (18-51 years) or middle-age (52-60 years) was associated with a better health status. The same pattern has been reported in individuals with or without chronic musculoskeletal pain; however, the significant ages were younger (20-33 years and 34-46 years) [36] compared with the present study.

Another important health factor was having no/small problem with the sleep structure. This also agreed well with the eight-year follow up of individuals with or without chronic musculoskeletal pain [36]. The conclusion of a review was that a good sleep is vital for the health and HRQL. However, the role of sleep is unfortunately not well explored [42]. These results indicate that a good sleep structure is an important domain to work within clinical practice. More research must be done on how to influence towards a better sleep structure for people with rheumatic diseases.

Other health factors were feeling painless, making low effort exercise more than two times per week, having emotional support and practical assistance, and having completed secondary school as highest education. Each of these factors predicted a better health status in only one of the SF-36 subscales. Other studies have shown the importance of these factors on the health status. It is well known that pain [20, 43] and a low education level [3, 31] are risk factors that could decrease HRQL, and that having emotional support could increase HRQL [31, 36]. The effect of exercise on HRQL is more complex, and there are no consistent results [7, 8, 14, 15]. There is nevertheless more evidence that exercise is beneficial than risky [15].

It was surprising that the diet, high and medium effort of exercise, performing hobbies, feeling sexual lust, alcohol habit, immigrant status, civil status, socioeconomic status - main occupation, socioeconomic status - current occupation and rheumatic disease were not affecting any subscale in the health status. In clinical practice patients often mention these factors as very important for their health status.

In the eight SF-36 subscales the mean changes were only deteriorations of 2.7-9.7 points after 12 months and if these few points are of clinical significance is controversial. Valuation of the clinical relevance of mean changes in SF-36 is ongoing [44] but there is a suggestion that effects larger than 12 % of the baseline value in SF-36 are assumed to be the minimal clinically important differences (MCID) [45]. In the present study there were >12 % deterioration in the subscale RP,
BP, VT, SF and RE. This could prove that the deterioration had a clinical significance for the individuals HRQL.

All the individuals in the present study had rheumatic diseases and had completed a multimodal rehabilitation when the study started. However, the aim was not to evaluate the rehabilitation but rather to find factors predicting a better health status 12 months after the rehabilitation in people with rheumatic diseases. It has been impossible to determine if any of these health factors were interacting with the rehabilitation program since there was no control group.

Finally, future longitudinal studies comparing health promoting factors are needed to confirm their impact on HRQL in people with rheumatic diseases. There is also a need for more studies about how individuals’ SOC could be strengthened and if health-care professionals could help them with that. Health factors as well as risk factors are important to address in clinical work. Strategies have to be formed to help people with rheumatic diseases to identify and strengthen factors like feeling rested after sleep, having a good sleep structure and having work capacity to improve their health status.

**Methodological considerations**

The number of individuals in the study did not allow for full multivariate models including all independent variables, so it was decided to introduce the variables in separate analyses, controlling for age, sex and baseline value of the SF-36 subscales. In lack of any known valid cut-point for good health in this population, when dichotomising the SF-36 subscales it was decided to use the mean value for each of the subscales as a cut-point, in order to get enough individuals in each group of the dependent variable.

As age and sex were likely to be confounders, these factors were controlled for in the analyses, together with the baseline values of the SF-36 subscales, to adjust for the possibility that outcome would reflect the baseline score and not a change over time.

There is a problem in the use of SF-36 that floor and roof effects can reduce the possible change over time in the extreme ends of the scales.

A limitation in this study was that a $p$-value of less than 0.05 was considered statistically significant; however, because of the many comparisons $p$-values showing a weak significance ($>0.01$) may appear by chance.

**Conclusions**

The most important health factors were having a strong SOC, feeling rested after sleep, having work capacity, being younger or middle-aged, and having no/small problem with the sleep structure. These health factors are important to put forward and address in clinical work with rheumatic diseases. Knowledge of factors predicting a good health outcome should be used to optimise treatment strategies.
Competing interests
The authors declare that they have no competing interests.

Authors' contributions
All authors contributed equally in designing the study, discussing the statistical framework, interpretation and discussion of the findings. SA and SB carried out the statistical analyses and drafted the manuscript. All authors read and approved the final manuscript.

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References


Figure 1 The SF-36 scores for people with rheumatic diseases. Comparison of the SF-36 subscales scores (mean values) for people with rheumatic diseases at baseline one week after rehabilitation and at the 12 month follow-up.

* = Significant change ($p<0.05$)
Table 1: Socio-demographic and supposed health-factors in a population with rheumatic diseases one week after rehabilitation.

<table>
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<tr>
<td>75-90 Very good</td>
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</table>

Group A: Manual workers  
Group B: Assistant no manual employees  
Group C: Intermediate/higher employees and upper-level executives  
Group D: Others
Table 2: Proposed health factors at baseline, and outcome in HRQL at the 12 month follow-up.

OR (95 % CI) in multivariate analyses of factors believed to affect HRQL (assessed by SF-36) in a positive way in a population with rheumatic diseases at a 12 month follow-up. Factors were controlled for age, sex and baseline SF-36 score but not for each other.

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<tr>
<th>PF</th>
<th>RP</th>
<th>BP</th>
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<th>SF</th>
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<tr>
<td>OR (95 % CI)</td>
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**Sex**
- Women: 1.0
- Men:
  - Age 70-88: 1.0 (0.4-2.3)
  - 61-69: 1.0 (0.4-2.3)
  - 52-60: 1.0 (0.4-2.3)
  - 45-51: 1.0 (0.4-2.3)
  - SF-36 at >mean baseline: 1.0
  - Feeling painless: 1.0
  - Sleep structure: 1.0
  - Feeling rested: 1.0
  - Diet: 1.0
  - High effort of exercise: 1.0
  - Medium effort of exercise: 1.0
  - Low effort of exercise: 1.0
  - Performing hobbies: 1.0
  - Feeling sexual lust: 1.0

**Age**
- Years:
  - 70-88: 1.0 (0.4-2.3)
  - 61-69: 1.0 (0.4-2.3)
  - 52-60: 1.0 (0.4-2.3)
  - 45-51: 1.0 (0.4-2.3)
  - SF-36 at >mean baseline: 1.0
  - Feeling painless: 1.0
  - Sleep structure: 1.0
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  - Diet: 1.0
  - High effort of exercise: 1.0
  - Medium effort of exercise: 1.0
  - Low effort of exercise: 1.0
  - Performing hobbies: 1.0
  - Feeling sexual lust: 1.0

**SF-36 at baseline**
- ≥mean: 1.0
- <mean: 1.0

**Sex**
- Women: 1.0
- Men:
  - Age 70-88: 1.0 (0.4-2.3)
  - 61-69: 1.0 (0.4-2.3)
  - 52-60: 1.0 (0.4-2.3)
  - 45-51: 1.0 (0.4-2.3)
  - SF-36 at >mean baseline: 1.0
  - Feeling painless: 1.0
  - Sleep structure: 1.0
  - Feeling rested: 1.0
  - Diet: 1.0
  - High effort of exercise: 1.0
  - Medium effort of exercise: 1.0
  - Low effort of exercise: 1.0
  - Performing hobbies: 1.0
  - Feeling sexual lust: 1.0

**Age**
- Years:
  - 70-88: 1.0 (0.4-2.3)
  - 61-69: 1.0 (0.4-2.3)
  - 52-60: 1.0 (0.4-2.3)
  - 45-51: 1.0 (0.4-2.3)
  - SF-36 at >mean baseline: 1.0
  - Feeling painless: 1.0
  - Sleep structure: 1.0
  - Feeling rested: 1.0
  - Diet: 1.0
  - High effort of exercise: 1.0
  - Medium effort of exercise: 1.0
  - Low effort of exercise: 1.0
  - Performing hobbies: 1.0
  - Feeling sexual lust: 1.0
Table 3: Proposed health factors at baseline, and outcome in HRQL at the 12 month follow-up. OR (95% CI) in multivariate analyses of factors believed to affect HRQL (assessed by SF-36) in a positive way in a population with rheumatic diseases at a 12 month follow-up. Factors were controlled for age, sex, and baseline SF-36 score but not for each other.

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<th>OR (95% CI)</th>
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Group A: Manual workers

Group B: Assistant no manual employees

Group C: Intermediate/higher employees and upper-level executives

Group D: Others

Study II
ORIGINAL RESEARCH

Experiences of health-promoting self-care in people living with rheumatic diseases

Susann Arvidsson, Stefan Bergman, Barbro Arvidsson, Bengt Fridlund & Anita Bengtsson Tops

Accepted for publication 18 December 2010

Abstract

Aim. This paper is a report of a study that explores and describes the meaning of the phenomenon of health-promoting self-care as experienced by people living with rheumatic diseases.

Background. People with rheumatic diseases estimate health status as low and health belief and health status influence self-care behaviours. Several self-care behaviours are used in the efforts to mitigate the diseases.

Method. The study had a descriptive phenomenological approach based on a reflective life-world perspective. Data were gathered in 2007 by unstructured open-ended interviews with 12 individuals living with rheumatic diseases.

Findings. The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to influence health in positive ways. Self-care was a way of life and implied being ready to understand and respond to signals from the body. Three inter-related constituents elucidated their experiences: dialogue, power struggle and choice. Self-care was experienced as dialogues with the body and with the immediate environment. In order to respond to signals from the body, power struggles were required to be entered into when fighting the diseases. Choices were required to be made and things that were beneficial for the body were prioritized.

Conclusion. In this study, the meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care was a way of life. This meant to be ready to understand and respond to signals from the body. Self-care required dialogues, power struggles and choices.

Keywords: adults, health promoting self-care, nursing, phenomenology, rheumatic diseases, self-care
Introduction

Globally, there are over 150 rheumatic diseases with a great variation in terms of severity and complexity (WHO 2008). Living with rheumatic diseases can mean severe pain, negative feelings (like sadness, unfairness, guilt), but also a focus on managing and recovery from the disease (Hwang et al. 2004, Maly & Krupa 2007, Mitton et al. 2007). It is common that people with rheumatic diseases estimate their health status as low (Da Costa et al. 2000, Neumann et al. 2000). Health status and health belief (McDonald-Miszczak & Wister 2005), but also different cultural traditions have been shown to influence choices of self-care behaviours in people with rheumatic diseases (Ibrahim et al. 2001, McDonald-Miszczak & Wister 2005). According to a caring perspective, adults have the ability to act in order to maintain health and to treat themselves in the event of illness or injury (Orem 2001). These abilities are learned through relationships and communication with other people and are conscious acts (Denyes et al. 2001, Orem 2001).

In people with rheumatic diseases, self-care is a multi-dimensional and complex process with a purpose to bring about order in their life. The process involves recognizing and monitoring boundaries of the body, mobilizing resources, managing the shift in self-identity, as well as balancing, planning and prioritizing in life (Kralik et al. 2004). It has been found that people with rheumatic diseases use several self-care behaviours in their efforts to mitigate the disease, maintain independence and prevent loss of valued life activities. Such self-care behaviours are, for example, adopting an acceptance of the disease, trying to have a positive attitude, exercising regularly, using alternative treatment methods and using distractions in activities that stimulate and maintain independence (Taylor 2001). People with rheumatic diseases learn how to respond to symptoms and consequences of the diseases by reflecting over the outcomes of successful or unsuccessful self-care behaviours (Kralik et al. 2004). Thus, personal and social resources are important when trying to tolerate and manage the burden of the disease (Malterud & Hollnagel 2004).

The previous research performed in South Korea (Hwang et al. 2004), Canada (McDonald-Miszczak & Wister 2005), United Kingdom (Mitton et al. 2007), United States of America (Ibrahim et al. 2001), Australia (Taylor 2001, Kralik et al. 2004) and Norway (Malterud & Hollnagel 2004) shows that self-care is important for health in people with rheumatic diseases all over the world. Despite this, there is little research from the perspective of how these people experience their self-care and what meaning they ascribe to self-care. From a clinical point of view and in order to increase the currently limited knowledge about why people with rheumatic diseases do not always do the recommended self-care, it is of interest to study how people living with rheumatic diseases experience health-promoting self-care.

The study

Aim

The aim of the study was to explore and describe the meaning of the phenomenon of health-promoting self-care as experienced by people living with rheumatic diseases.

Design

The present study had a Husserlian phenomenological approach (Husserl 1913/2004) based on a reflective life-world perspective (Merleau-Ponty 1945/2004). The purpose of a phenomenological reflective life-world perspective is to come close to and describe the essence or general structure of the phenomenon in a clear and comprehensible way, to expand and deepen the understanding about the individual’s lived experience (Dahlberg et al. 2008, Giorgi 2009).

Participants

The inclusion criteria were that the individuals were registered as patients at a rheumatology unit in the southwest of Sweden, had one or more diagnosis of rheumatic diseases for more than a year, understood and spoke Swedish, and had not been cared for by the first author. In this purposeful sample the variations of experiences were guaranteed by strategically selecting with regard to gender, age, rheumatic disease and ethnicity (Dahlberg et al. 2008). Thus, 12 individuals were strategically selected from the waiting list for regular visits to the rheumatologists. The mean age for the six women was 43 years (37–51 years) and for the six men the mean age was 55 years (39–73 years). Two of the individuals were born in other countries than Sweden, one from South America and one from Central Europe. The individuals' diagnosed rheumatic diseases were ankylosing spondylitis, polyarthritis, polymyalgia rheumatica, psoriatic arthritis, rheumatoid arthritis (RA), reactive arthritis, scleroderma, Sjögren’s syndrome and systemic lupus erythematosus.

Data collection

The data collection took place January to May in 2007. All the individuals were telephoned by the first author in order to give information about the aim of the study and ask if they
wanted to participate. The individuals received both verbal and written information about the voluntariness to participate, to withdraw from the study at any time and they were guaranteed confidentiality. All selected individuals chose to participate and written informed consent was obtained. The interviews were carried out by the first author in an undisturbed place in the individuals’ homes or at the rheumatology unit, but not in connection with any visit to caregivers. These interviews lasted between 80 and 135 minutes and were tape recorded.

According to a phenomenological approach, the research interviews needed to be guided by openness and adherence to the phenomenon under study (Giorgi 1997, 2009, Dahlberg et al. 2008). Unstructured interviews were therefore used. All interviews started with an initial question: ‘Can you tell me about any situation where you felt that something you did was improving your health?’ In order to reach depth in data and let the individuals reflect over their answers follow up questions like: ‘How do you think when you say....?’ and ‘What does it mean for you?’ were asked.

Ethical considerations

This study conformed to the principles outlined in the Declaration of Helsinki (WMA 2008). The study was approved by the Ethics Research Committee, Faculty of Medicine, Lund University, Sweden, dnr 566/2006. All interviews were coded to protect the anonymity of the individuals and were transcribed verbatim by the first author. The translation of the interviews into English was made carefully so the original meaning was not altered.

Data analysis

The descriptive analysis of data material followed the phenomenological approach as described by Giorgi (1997, 2009) and Dahlberg et al. (2008). Initially, and in order to gain an overall impression of the material, the interviews were interrupted and read several times until the authors felt familiar with the material. The sense of the whole was important before starting to examine the parts. Subsequently, each transcribed interview was divided into smaller parts, meaning-bearing units, in relation to the studied phenomenon health-promoting self-care. Based on the variations of differences and similarities, the meaning-bearing units were organized in order to see and understand patterns, clusters of meanings (Dahlberg et al. 2008). As the analysing process moved forward from concreteness to a more abstract level of understanding, the clusters of meanings were synthesized into a structure or pattern in which they were bound together. In this phase, the essence of the phenomenon health-promoting self-care started to emerge.

The essence, the very core of the phenomenon and its constituents with an aim to describe and clarify the essence, were thus analysed in relation to each interview, meaning-bearing units and clusters of meanings. The constituents could not be separated; they were intertwined with each other and with the essence (Dahlberg et al. 2008). According to a phenomenological approach, data were openly analysed by flexible moving between the whole – the parts – the whole of the interviews (Giorgi 1997, 2009, Dahlberg et al. 2008).

Rigour

The phenomenological method was chosen due to its openness and strength in describing experiences without attempting to interpret them (Dahlberg et al. 2008). The credibility was strengthened when the last author scrutinized every transcribed interview before the next interview was done by the first author, to be sure that the questions in the interviews were in accordance with the aim of the study. The sample size was not decided on beforehand, but was determined to the extent the individuals had the ability to provide rich and deep data. To strengthen the dependability, the first and last author, who were familiar with the method, began to analyse the data separately and then compared the concordance of the findings. The conformability of the results was considered in all stages of the study when the authors tried to restrain or bracket their pre-understanding due to, for instance, their experiences of working with rheumatology care, living with a rheumatic disease or having relatives or friends who were living with a rheumatic disease (Polit & Beck 2010). All authors had different professional, clinical and theoretical background, and were involved in most steps of the study. The authors’ personal beliefs, theories and assumptions were always put under consideration and critical reflection in order to encounter data in an open manner (Giorgi 1997, 2009).

Findings

Initially, in the findings section the essence of the phenomenon health-promoting self-care in people living with rheumatic diseases will be presented. The essence is followed by its three constituents, dialogue, power struggle and choice, which describe and clarify the essence. The constituents are described and illustrated by quotations from the interviews.

The essence of the phenomenon health-promoting self-care

For people living with rheumatic diseases, self-care takes place against a background of continual hope and belief in a
future ability to influence health in a positive way. Health is experienced as a harmony and to be in balance with the body, as well as in all other aspects of life like the individual's social life.

Self-care is a way of life and means being ready at all times to respond to signals from the body, such as tiredness, sadness, stiffness and pain. Such signals need to be interpreted and understood as indicators on actions that are needed to alleviate the problem(s). Self-care means an inner dialogue where physical, emotional and cognitive aspects of the body are considered. It is equally a dialogue with previous social, cultural and religious memories, and experiences of life, as well as with other people such as family members, colleagues and friends, mass media, and written word in books or on the Internet.

The meaning of self-care can also be described as a power struggle within the individual between the desire to be free from the rheumatic disease and the concrete fact that the symptoms indicate that the disease is a part of the body. People living with rheumatic diseases strive and force themselves to fight the illness and its concrete consequences in order to attain well-being and health. The power struggle takes place within the body, between its possibilities and limitations, and the meaning of the power struggle is to obtain control over the body.

The meaning of self-care is to make rewarding or beneficial choice. The choice implies a dialectic process where previous experiences are carefully balanced against the will to change and challenge the lack of well-being caused by the diseases. Trust in oneself and belief in one's own ability to choose health-promoting self-care are crucial for the choice. Although the choice between different self-care approaches is not always clear and straightforward, the choice is invariably aimed at generating some form of recompenses for the body related to health and well-being. Rewarding or beneficial choice increases the self-confidence and the self-esteem.

Dialogue

The meaning of self-care for people living with rheumatic diseases is to be in a constant ongoing dialogue with the body, where emotions, thoughts and stimuli of the senses can be known and heard. The dialogue is experienced like an open attention to bodily signals by reasoning about, listening to, observing and analysing these. It occurs against the background of a desire to understand the signals' origin and consequences. The dialogue reveals and highlights, for example, signals indicating well-being such as peacefulness and joy, as well as discomfort such as pain, feelings of weakness and worry. The meaning of the dialogue is to evaluate various bodily signals in order to decide whether to apply previously used self-care such as rest, walks and medication and/or whether to search for and test new forms of self-care.

I noticed that I didn't have the strength to prepare the food I wanted and needed... that my body needed, my cells needed to regenerate themselves. And then I started to read about nutrition...vitamins, minerals, everything about the cells/... Inner strength alone is not enough. (Individual 5)

In the dialogue with the body, physical signals can sometimes dominate and the individual's emotions and intentions come in the background. On these occasions, the body may be experienced as if the body had its own way of functioning. In order for the individuals to perform self-care, they need to understand how the restricted body functions. Understanding emerges in the dialogue and requires willingness, time and an ability to listen calmly and wait until the signals emitted by the body become clearer.

I wait for it (the body). Yes, I brood and wait to see what will happen/...I just wait and try and see what kind of pain it is. (Individual 3)

The dialogue sometimes demands silence. It facilitates the listening to the body. Silence makes signals clearer and minimizes risk of disregarding significant signals. When listening, the individual becomes observant and aware of both strong and weak signals of pleasure or discomfort emitted by the body. During the dialogue, feelings of astonishment, joy and frustration emerge, due to which the body does not react in its usual way.

I pursued sports, exercised and things like that ...and I always had setbacks in that my knees did not hold...while at the same time I felt that I needed to get some exercise. (Individual 8)

On such occasions, the changeableness of the body and its unpredictability become obvious. Learning on the basis of an understanding of one's own body as being in a state of permanent transformation is one meaning of the dialogue. The dialogue can also arise in relation to the immediate environment, such as information from mass media, written texts in books, newspapers, and on the Internet, as well as in conversations with other people. Feelings of togetherness and fellowship emerge when being in a dialogue with others, whereby feelings of loneliness are eclipsed and a sense of being like others and being needed is created.

Like the woman over there...we were having coffee and chatting about diseases.... That she was feeling so unwell and one thing and the other and she was so negative. ...But you can change it, I said... I
Power struggle

The meaning of self-care for people living with rheumatic diseases is a power struggle between the symptoms and consequences of the disease in everyday life, and the individual’s will to experience well-being and regain control over the body. The individual wages a battle against the health problems caused by the disease by sometimes limiting wishes, desires and urges as well as resisting temptations. The power struggle means negotiation between degrees of control and discipline with the urge to give into desires and wishes.

When I put my foot outside the door I initially feel that I have no strength, but after having done my first round...my body gradually becomes warmer and then... My joints become more supple. Yes, my whole body feels lighter. It’s essential to go out. Irrespective of how you feel. You just have to make a move and do it. (Individual 5)

The individual experiences being in control when the body responds to self-care in the way expected and the control has been preceded by searching for and challenging the boundaries of the body. The power struggle takes place within the body, i.e. between the physical body, soul and spirit in addition to the individual’s social life, a process that takes time.

I can never let it (the disease) control me, I prefer to...try to turn it into something positive...actually... One tries to pep them up... and it makes me feel good too. (Individual 7)

Choice

The meaning of self-care for people living with rheumatic diseases involves a process of making continuous choices, about whether or not to perform self-care or whether or not to listen to the signals of the body or the immediate environment. The choice is governed by positive or negative experiences of previous self-care, as well as the will to change illness caused by the disease. The choice demands, as well as generates trust and belief in a person’s own ability and knowledge about how one’s body is functioning.

It (the chosen training) has taught me, I have learnt about me. About my body. I am at one with my body. I don’t leave my body in the hands of other people. I’m working with it and see the difference... in the mirror. (Individual 5)

When making the choice, the individual prioritized self-care that generates joy, energy and satisfaction as a result of, for example, reduced pain and stiffness, i.e. self-care that is experienced as a reward and/or a beneficial for the body. These experiences of different rewards and benefits govern future choices of self-care and afford trust and belief in a person’s own ability to choose self-care that promotes well-being.
Sometimes you actually have to struggle to achieve certain goals. Sometimes it can be worth it. It’s like those who... climb Mount Everest. It’s hard work... But when they get their rewards... When they have reached the summit... Then it’s a feeling of freedom... And strength... Every step you take leads to an experience of being rewarded. (Individual 9)

When the choice of self-care fails to generate a benefit or reward for the body, a feeling of powerlessness emerges. The individual has to make a halt and start a dialogue with the body to find out what the next choice shall be. Sometimes the choice stands between safe and familiar self-care or more exciting and untested self-care. The choice of safe, familiar and well-tested self-care means that there is an assumption about the body to be predictable. The choice gives desired effects, whereas the choice of exciting and untested self-care is driven by a hope of finding new ways of overcoming the disease. This means an uncertainty and risk-taking, although experienced as stimulating, mainly because the outcome can be a positive surprise.

She (a zone therapist) talks a lot about her natural cures and suchlike. And I couldn’t do like this (raises one arm)... so I started to go to her and attended five treatment sessions and received a bottle of pills and I haven’t had the problem since. As I got rid of the problem, what am I to think? After all, I have to believe in it, I only did it once...and it worked. (Individual 11)

The meaning of the choice is to try and challenge the safe, familiar and well-tested self-care, but also sometimes dare to combine it with exciting and untested self-care in an unfamiliar territory. The choice of self-care is influenced by many factors; in addition to previous experiences, it can also be affected by how previous generations of the individual’s family dealt with ill health and achieved well-being.

I don’t know how I became aware of that resting ...I suppose I was tired then (at noon), (laughing)...and wanted to have a rest. My grandparents always did that. They toiled and worked hard and were farmers. And they always took a rest after dinner. Took a break then, a siesta...//After eating and digesting, I feel better when I have rested for a while. I actually think it’s good. (Individual 2)

The meaning of the choice is also to lessen monotony and boredom in self-care. The choice of self-care is not governed by knowledge about the most suitable form, but by whether or not it is experienced as enjoyable and inspiring for the body. When making the choice, the individuals are especially concerned not to experience themselves as ill, they want to be like everyone else.

I think that you feel more ill when you go there (the physiotherapy at the health care centre)... than when attending an ordinary gym. ...You feel that you are...the same as everybody else in an ordinary gym...even if you can’t lift as much. But when you are here, only cripples come here... Then you feel that, I come here because I’m ill... And when you feel after three weeks that the condition hasn’t improved, you feel... I won’t bother to go... I can go to an ordinary gym and feel... I can manage it all right. But I still haven’t managed to improve those small muscles that she (the physiotherapist) is after...but I can manage regardless. (Individual 12)

Discussion

Study limitations

To some extent, only 12 individuals being interviewed may be seen as a limitation, but the interviews presented a comprehensive amount of meanings of the phenomenon health-promoting self-care. The authors are therefore inclined to believe that the findings presented here is of interest to healthcare professionals and other people with rheumatic diseases.

Experiences of the phenomenon health-promoting self-care

New in the present study is that people who lived with rheumatic diseases experienced the phenomenon health-promoting self-care as a way of life and that it meant to be ready at all times to understand and respond to signals that the body sends out. The self-care required that dialogues, power struggles and choices were made. The background to the self-care was a continual hope and belief in their ability to influence the health in a positive way. The continual hope and belief mean that self-care is constantly in progress and development, and that the individuals exhibit a tremendous capacity.

The findings from the present study agreed well with Orem’s self-care theory, which describes self-care as a process. This process consists of actions of investigating, formulating and expressing requirements, but also making judgements about what should be done. When individuals perform actions, it requires essential power that was activated through stimuli (Denyes et al. 2001, Orem 2001). In the present study, self-care was described as a power struggle between the individual and the rheumatic diseases, but also in relation to other people. The power struggle was within the body, between its possibilities and limitations, and the meaning was to obtain control over the body. This is a finding supported by Kralik et al. (2004) and Taylor (2001) who demonstrated that self-care was a constant planning and managing of daily life as a meaning of creating order. The present study and Kralik et al. (2004)
What is already known about this topic

- It is common that people with rheumatic diseases estimate their health status as low, and their health status and health belief influence the choice of self-care behaviours.
- People with rheumatic diseases can make use of several self-care behaviours in their efforts to mitigate the diseases.
- Self-care is a multidimensional and complex process for people with rheumatic diseases, where the purpose is to bring about order in their lives.

What this paper adds

- The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to influence health.
- Self-care was experienced as a way of life and meant to be ready to listen, understand and respond to signals from the body indicating well-being or discomfort.
- Three inter-related constituents elucidated the experiences of health-promoting self-care: dialogue, power struggle and choice.

Implications for practice and/or policy

- The findings give a new perspective of self-care that may deepen the understanding of healthcare professionals, but are also beneficial and supportive to people living with rheumatic diseases.
- The perspective is important to take into account when planning and starting patient education about health-promoting self-care to people living with rheumatic diseases.

show that action to initiate order or obtain control is not a single act; instead is it a combination of processes carried out over a period of time.

In the present study, health-promoting self-care as experienced by people living with rheumatic diseases also required that they made choices, the essential means of which were to generate some form of reward for the body in order to increase the possibilities to improve the well-being and health. These choices in turn required that previous experiences were balanced carefully against the desire to change and challenge the lack of well-being caused by the diseases. This agreed well with the findings from Kralik et al. (2004) where people learned about their responses to diseases through the experiences and as a result of trial and error. They learnt about their personal limitations or boundaries and could then make decisions how they should plan and prioritize (Kralik et al. 2004). In order to experience good health, people with various disabilities need to be able to build and maintain a sense of balance between body, mind and spirit, as well as between their social context and environment (Albrecht & Devlieger 1999). This agreed well with the findings from the present study where the individuals experienced health as a harmony and to be in a balance with the body. The body means a unit of the physical body and soul, as well as the individual’s social life. The individuals experienced that the body could not be shared in various parts – everything was connected. Their experiences agreed well with Merleau-Ponty’s philosophy where the physical and the psychological are described as an interwoven unit, the lived body. The lived body is then in constant interaction with the world (Merleau-Ponty 1945/2004).

In the present study, health-promoting self-care as experienced by people living with rheumatic diseases required trust in oneself and belief in one’s own ability to make choices. Backman and Hentinen (2001) have found that high self-esteem was predicting a responsible self-care behaviour style. Feeling of togetherness, fellowship and being like others were important for the choice of self-care in the present study and two other studies found that the individuals acquired a power of life from people around them (Hwang et al. 2004, Hadert & Rodham 2008). This was also in agreement with Malterud and Hollnagel’s (2004) findings where personal and social resources were essential means for tolerating and managing the burden of diseases.

Previous research has shown the effectiveness of exercise on health for people with RA, but the evidence for other self-care interventions has been absent or weak (Vliet Vlieland 2007). The present study offers new insights about self-care. The meaning of self-care was much more than exercise. Self-care was an internal dialogue with the body, but also an external dialogue with the immediate environment. In order for the individuals to perform self-care, they needed to understand how the restricted body functioned. This understanding required time, willingness and the ability to wait in an active way until the signals emitted by the body became clearer. Often there is no time in clinical practice to give patients the opportunity to have internal and external dialogues; instead there is often an unspoken requirement on the patient to listen, accept and to do what is recommended (Arborelius 2001). It has been shown that patients with RA want to be informed and that they express a great need for information about the disease and its treatments.
(Neame et al. 2005), but they do not always understand the information (Hadert & Rodham 2008). It is important that healthcare professionals find ways of checking the level of patients’ understanding and only after that could they support and empower the patients to do self-care (Hadert & Rodham 2008). All these findings can be useful to bring into rheumatology care and our claim is that the new knowledge from the present study can be beneficial to healthcare professionals. Unfortunately, there is a great lack of studies about how to take advantage of the individual’s personal and social resources.

Conclusion

In the present study, the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases was that self-care was a way of life, and it meant to be ready at all times to understand and respond to signals from the body. Self-care required dialogues, power struggles and choices. Further studies are needed to find the best way in clinical practice to support people with rheumatic diseases to do and be able to continue with health-promoting self-care.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

SA, SB, BA, BF and ABT were responsible for the study conception and design. SA performed the data collection. SA and ABT performed the data analysis. SA was responsible for the drafting of the manuscript. SB, BA, BF and ABT made critical revisions to the paper for important intellectual content. SA obtained funding. SB provided administrative, technical or material support. SB, BA, BF and ABT supervised the study.

References


**Study III**

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Effects of a self-care promoting problem-based learning program as reported by people with rheumatic diseases: a randomized controlled pilot study

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Abstract

Objective:
The aim of this pilot study was to evaluate the effects of a self-care promoting problem-based learning (PBL) program for people with rheumatic diseases, in terms of health-related quality of life (HRQL), empowerment and self-care ability at a six month follow-up.

Methods:
A randomized controlled design was selected with pre-test, one-week and six months post-test after the one-year PBL-program. The participants were randomly assigned to either the experimental group (n=54) or the control group (n=148). The differences were analyzed by t-test and Pearson Chi-square.

Results:
The participants in the experimental group had stronger empowerment after participation in the PBL-program compared with the control group. There were no differences in HRQL, self-care ability, sense of coherence, pain, quality of sleep or fatigue between the groups. The participants in the experimental group stated they had implemented lifestyle changes they had not done without the PBL-program.

Conclusion:
The present self-care promoting PBL-program enabled people with rheumatic diseases to improve their empowerment but not their HRQL and self-care ability compared with the control group.

Practice Implications:
It is important to continue to develop PBL in patient education in order to find the very best way to use this pedagogical model in rheumatology care.

Keywords:
Rheumatic diseases, self-care, empowerment, problem-based learning, patient education
1. Introduction
There are over 150 rheumatic diseases in the world with a great variation in terms of severity and complexity [1]. The various rheumatic diseases differ in cause, course and treatment, as well as most of the diseases attack the musculoskeletal system but also often other organic systems [2, 3]. It is a common factor for people with rheumatic diseases such as fibromyalgia [4, 5], systemic lupus erythematosus (SLE) [6, 7] and rheumatoid arthritis (RA) [8, 9] to estimate the health-related quality of life (HRQL) low. Pain, sleep disturbances and fatigue are some of the most important influencing factors on the HRQL for people with RA [10].

It is important for people with rheumatic diseases to maintain independence [11] and the ability to find appropriate self-care is related to how strong belief in their abilities they have [12, 13]. The process when individuals receives more control over decisions and actions that affects their own life and health is often described as empowerment [14]. An empowerment approach involves helping the individual to learn to think critically and to make informed decisions [15]. If an individual experiences life as understandable and manageable as well as meaningful in dealing with problems that arise, then this individual has a greater ability to stay healthy and to have a strong sense of coherence (SOC). The most important determinant for SOC is personal relationships [16, 17].

Individuals with RA express a great need for education, support and assistance in adapting to the disease [18] but the current patient educations have no evidence of long term benefits [19]. The goal of patient education is that the individuals must participate actively in their care and have knowledge and skills to manage their self-care in the best way [20]. Group teaching is a great way to teach the ability to problem solving and self-care [21]. Problem-based learning (PBL) is an example of a pedagogical model for group teaching [22, 23]. In patient education has PBL been proven to be a useful way to give patients a better understanding and motivation to influence their own behavior to better health [24, 25]. At a 12 months follow-up, after a problem-based patient education, patients with RA had easier to manage pain and other problems with the disease, compared with the control group [26]. Women with fibromyalgia and other non-malignant pain strengthened their internal resources after participation in problem-based rehabilitation [27]. Besides these studies there are few studies in rheumatology care where the used pedagogical model of learning is described. There is a great need to improve and develop the quality of current patient education [19]. People with rheumatic diseases should have an opportunity to improve their ability to acquire and apply knowledge. This could then increase their belief in their abilities to find self-care strategies and improving their empowerment and HRQL. The aim of this pilot study was therefore to evaluate the effects of a self-care promoting PBL-program for people with rheumatic diseases, in terms of HRQL, empowerment and self-care ability at a six month follow-up.

2. Methods
2.1. Design
A randomized controlled design was selected with pre-test, one-week and six months post-test after a one-year self-care promoting PBL-program for people with rheumatic diseases who had chronic musculoskeletal pain, sleep disturbances and/or fatigue.

2.2. Intervention
The PBL-program was run alongside the usual standard care the participants received at a rheumatology unit. The standard care was depending on for instance the participants’ diagnosis and the severity of the disease but also what treatment the participant preferred. The
participants in the experimental group were divided consecutively into seven groups of seven or eight participants and one tutor. Each group met for one and one half hours, ten times in a one-year period.

Proposals and comments from six other individuals with rheumatic diseases who participated in a focus-group interview but also results from other studies [24, 25] were used when developing the curriculum for the PBL-program. Following starting points which were linked to self-care when people with rheumatic diseases had chronic musculoskeletal pain, sleep disturbances and fatigue were determined in the curriculum: self-awareness and self-confidence, relationships to other, stress and relaxation, physical activity and rest, medicines and herbal remedies, tobacco and alcohol, and food and drink. Each group could also discuss further areas they considered as important.

The purpose of the PBL-program was that the participants had to investigate an approach to learning, take self-responsibility for learning, find functional knowledge, think critical, and find a way of lifelong learning and self-evaluation. The participants were then expected to get an opportunity to find approaches to self-care and to be able to handle the chronic musculoskeletal pain, sleep disturbances and fatigue and thereby improving their HRQL and the belief in their own ability.

At the first meeting focus was on describing and discuss the pedagogical model of PBL, the content of the program, the role of the tutor, how to organize the group work, and to set up a “co-operation contract”. Then to start the learning process, the tutor presented a situation or event (scenarios) and the group discussed their experiences and raised thoughts. A structured problem-solving process described by Tingström et al. [24] was used to stimulate the individuals to dare to be active in the discussions, ask questions, activate prior knowledge and appraise the newly gained knowledge and its application in their own lives [24, 25]. The used structured problem-solving process was “1) Scenario, clarify terms and concepts, 2) Brainstorming, 3a) Organize in problem areas, 3b) Scrutinize and evaluate knowledge, 4) Select one or more questions, 5) Specify learning needs, 6) Self-studies, 7) Discuss, scrutinize and synthesize newly-acquired knowledge, 8) Apply newly-acquired knowledge in your own life, 9) Evaluation, 10) Continue problem-solving” [24] (p. 326).

In order to clarify the self-directed learning, each participant wrote targets for their learning and self-care activities in a workbook. The tutors gave suggestions about how and where to search for learning materials. The group had in addition to the self-directed learning an opportunity to ask a resource person in rheumatology care, such as a physician or a physiotherapist, to come to a meeting and answer specific questions. This was not used but a physician, specialist in chronic musculoskeletal pain, gave a lecture which was based on questions from all the seven groups.

Three nurses were trained in PBL and each nurse was tutor for two or three groups. The tutors did not have a traditional role of teachers or experts, their role were to support the participants in the problem-solving process. The tutors received support every two months by the last author. The first author supported the tutors once a month but had also individual meetings when needs were aroused.

2.3. Participants
The inclusions criteria were having one or more diagnoses of rheumatic diseases for more than a year, having had musculoskeletal pain, sleep disturbances and/or fatigue during the last
three months, understanding and speaking Swedish, and wanting to participate in the PBL-program.

A cover letter, an “inclusion questionnaire” and an informed consent were sent to 800 registered patients at a rheumatology unit in the southwest of Sweden. The completed informed consent and the “inclusion questionnaire” were sent back. In case of no answer after three weeks, a reminder was done with a telephone call from the first author. A similar procedure was carried out at all three study tests.

The individuals who met the inclusion criteria and had completed the pre-test (n=202) were randomly assigned to either the experimental group (n=54) or to the control group (n=148). There were 51 participants who began in the PBL-program and there were 38 participants (75%) at the one-week post-test. The drop-out were due to medical reasons, difficulties to get away from work, economic reasons, disliked the group dynamics or the pedagogical approach. In the control group there were 131 participants (89%) at the one-week post-test. There were 38 participants (75 %) in the experimental group and 124 (84 %) in the control group at the six months post-test (Figure 1).

At the inclusion to the study there were 598 individuals who decided not to participate, of whom 225 (38 %) were men and 373 (62 %) were women. Their age was between 17-83 years with a mean age of 54.2 years (SD 14.3). There were 389 voluntary explanations from the individuals not participating in the study. They were, for instance, the work situation (n=93, 24 %), not having any of the inclusion problems (n=89, 23 %), residing too far from the hospital and with no economic compensation (n=54, 14 %), having the inclusion problems but not wanting to participate (n=47, 12 %), only problems with pain (n=31, 8 %) or feeling too weak (n=23, 6 %).

2.4. Instruments

Pre-test, one-week and six months post-test after the one-year PBL-program were conducted by completion of a questionnaire with various validity and reliability tested instruments. The areas covered were HRQL, empowerment, self-care, SOC, chronic musculoskeletal pain, quality of sleep, fatigue and demographic variables. HRQL was assessed by the Short Form-36 Health Survey (SF-36) in the Swedish standard edition [28] which has demonstrated good reliability and validity [29-31]. The SF-36 gives eight subscales assessing different aspects of HRQL: Physical Functioning (PF), Role – Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role – Emotional (RE) and Mental Health (MH). The score for each of the eight subscales ranged from 0 to 100. A higher score indicated better health [28]. Empowerment was assessed by the Swedish Rheumatic Disease Empowerment Scale (SWE-RES-23) which has five subscales assessing different aspects of empowerment: subscale 1 - Goal achievement and overcoming barriers to goal achievement, subscale 2 - Self-awareness, subscale 3 - Managing stress, subscale 4 - Assessing dissatisfaction and readiness to change, and subscale 5 - Support for caring. The items are scored on a five point Likert-scale ranging from strongly disagree (1) to strongly agree (5). A higher value indicated a stronger empowerment. This new instrument has demonstrated acceptable reliability and validity [32]. Self-care was assessed by the Appraisal of Self-Care Agency Scale (ASA-A) which assesses self-care ability. The total range of the ASA-A scale is 24 to 120 points. A higher score indicated better self-care ability [33]. The Swedish version has demonstrated good reliability and validity [34, 35]. Sense of Coherence was assessed by the SOC-questionnaire with 13 questions. These questions measure comprehensibility, manageability and meaningfulness, which show the level of SOC. The total range of the SOC
scale is 13 to 91 points. A higher score indicated better SOC [17, 36]. The Swedish version has demonstrated satisfying reliability and validity [37-39]. Chronic musculoskeletal pain and fatigue were assessed by a visual analogue scale (VAS), 0 to 10. A higher score indicated worse pain or fatigue. Quality of sleep was assessed by four questions used in previous studies [40-42]. The demographic variables were sex, age, civil status, education, residence, socioeconomic status (main and current occupation) and rheumatic disease. The participants in the experimental group also completed a questionnaire consisting of 18 questions about the quality of the PBL-program at the one-week post-test. This questionnaire concerned questions about for instance the content of the PBL-program, the problem-solving process, the learning process, the group process and lifestyle changes. Most questions had five possible scores ranging from a “very small degree” to a “very large degree”.

2.5. Statistical procedure and analysis
The statistical package SPSS for Windows, Release 18.0 was used. The Pearson chi-square test was used to explain the characteristics of the studied population and comparisons between groups. The independent t-test was used to measure differences between the groups at the same measurement occasion. A $p$-value of less than 0.05 was considered statistically significant. The power calculation with a 25% possible of drop outs showed that 150 individuals in the experimental group and 390 individuals in the control group would be enough. In this pilot study the group size of 54 individuals in the experimental group and 148 in the control group was therefore approximately one third of the estimated number of participants in the power calculation. The power calculation was based on the analysis of the SF-36 vitality scale and a power of more than 80% at a two-tailed test, a significance level of 5% and an assumption that the minimum difference between the groups was 6 points and the maximum standard deviation was of 20 points [43]. The actual number in the study was though sufficient to detect a clinical relevant minimum difference of 10 points with a power of 88%.

2.6. Ethics
The study was approved by the Regional Ethical Review Board in Lund, Sweden, dnr 560/2008. This study was registered at http://clinicaltrials.gov with the identifier number NCT00803491.

3. Results
There was an equal predominance of women in both the experimental group (71 %) and in the control group (73 %). The mean age was 56.4 years (SD 7.2, 37-68 years) in the experimental group and 55.2 years (SD 13.2, 21-78 years) in the control group. There were more participants in the experimental group who lived in a rural area (Table 1).

HRQL was assessed by the SF-36 eight subscales and there were no statistically significant differences between the experimental group and the control group and these subscales at the pre-test, the one-week post-test and the six months post-test (Table 2).

Empowerment was assessed by the SWE-RES-23 total score and its five subscales. At the one-week post-test the experimental group scored statistically significant higher means than the control group in the SWE-RES-23 total score ($p=0.005$) and in three SWE-RES-23 subscales: subscale 1 - Goal achievement and overcoming barriers to goal achievement ($p=0.001$), subscale 2 - Self-awareness ($p=0.017$) and subscale 4 - Assessing dissatisfaction and readiness to change ($p=0.014$). At the six months post-test the experimental group scored statistically significant higher means than the control group in the SWE-RES-23 total score.
(\(p=0.038\)) and in two SWE-RES-23 subscales: subscale 2 - Self-awareness (\(p=0.036\)) and subscale 3 - Managing stress (\(p=0.004\)) (Table 2).

Self-care ability was assessed by ASA-A and sense of coherence was assessed by SOC. There were no statistically significant differences between the experimental group and the control group in the pre-test, the one-week post-test and the six months post-test in terms of ASA-A or SOC (Table 2).

There were no statistically significant differences between the experimental group and the control group in the pre-test, the one-week post-test and the six months post-test in terms of feeling pain the last week, feeling fatigue the last week, not falling asleep at night, waking during the night, not feeling rested after sleep or waking too early.

The participants in the experimental group scored that they had belonged to a group that worked well together in a fairly high degree (\(n=15, 39.5\%\)) or in a sufficient degree (\(n=10, 26.3\%\)). The participants described that they felt involved, felt a community and security in the group, and that it was interesting to exchange experiences and knowledge. They also described that all participants were not enough active or engaged. The dropouts and absences disrupted the work in the groups. The participants scored that they used the material they had sought between the group meetings in a fairly high degree (\(n=14, 36.8\%\)) or in a sufficient degree (\(n=12, 31.6\%\)). They scored that they had concrete goals for lifestyle changes during the PBL-program in a fairly high degree (\(n=11, 28.9\%\)) or in a sufficient degree (\(n=15, 39.5\%\)). The participants had implemented these lifestyle changes in a fairly high degree (\(n=8, 21.1\%\)), in a sufficient degree (\(n=17, 44.7\%\)) or in a fairly small degree (\(n=9, 23.7\%\)) during the program. Examples of lifestyle changes were: trying to think more positively, thinking of their selves, being more physically active, changing in sleeping habits and food habits, reducing the use of pills and reducing the smoking. The participants scored that they had implemented these lifestyle changes in a very small degree (\(n=9, 23.7\%\)), in a fairly small degree (\(n=14, 36.8\%\)) or in a sufficient degree (\(n=12, 31.6\%\)) without the PBL-program.

4. Discussion and Conclusion
4.1. Discussion
This pilot study shows that the participants in the experimental group scored at the six month follow-up increased empowerment after participation in a one-year self-care promoting PBL-program compared with the control group. Both groups had got the usual standard care for people with rheumatic diseases. There were no impacts on HRQL, self-care ability, SOC, pain, quality of sleep or fatigue after the PBL-program for the experimental group compared with the control group. However, the participant in the experimental group stated that they had implemented lifestyle changes which they had not done without the PBL-program.

There were statistically significant differences in empowerment as measured by SWE-RES-23 between the experimental group and the control group. There were only small differences in the mean values, but we are inclined to believe that the participation in the PBL-program helped the participants to improve their empowerment and that it also have clinical significance. Especially when three-fifths of the participants scored that they had implemented the lifestyle changes in a very small or fairly small degree without the PBL-program. These lifestyle changes were perhaps possible because of the improvements in self-awareness (SWE-RES-23, subscale 2) and in managing stress (SWE-RES-23, subscale 3). The self-awareness was covered by self-knowledge, motivation and knowledge of how to make the necessary self-care choices and if it was worth it, and the managing stress was
covered by positive and negative coping with rheumatic diseases related stress. These results agreed well with Andersson et al.’s description that an empowerment based intervention involving facilitating and supporting the participants to reflect their experiences could enhance the participants’ awareness and consequences of the self-care decisions. Empowerment is a continuous variable and the strength and direction of change shows the intervention’s effectiveness [15].

In an empowerment approach the participant is involved in problem formulations, decisions making and actions. Thus, the health-care professionals have to refrain some of their control and power over for instance the participant’s disease and treatment [44]. Andersson et al. states that “Empowerment occurs when health-care professionals’ goal is to increase the capacity of patients to think critically and make autonomous, informed decisions. Empowerment also occurs when patients are actually making autonomous, informed decisions about their […] self-management” [15] (p. 277). In the rheumatology care is empowerment an approach which has not received much attention. This study confirms that empowerment is an approach which is necessary to study more, especially in patient education. Further, it is also necessary to test the new instrument SWE-RES-23 [32] more but also to develop other empowerment instruments.

The result in this study could not show that there was a difference in the self-care ability measured by ASA-A, after participation in the PBL-program but two-thirds of the participants in the experimental group stated that they had implemented lifestyle changes in a fairly high or sufficient degree during the PBL-program. The next step will therefore be to consider how existing instruments measures the self-care ability and lifestyle changes and if these instruments could be improved and further developed.

In terms of lifestyle changes have Fontaine et al. shown that it is less than two-fifths of the individuals with arthritis who reported that they were meeting the public health recommendations for physical activity [45]. The main factors for better self-care in a general population were knowledge and understanding. Health-care professionals, but also family and friends are important sources of information, guidance and support for self-care [46]. These results show the importance of including, for instance, the family in the next upcoming PBL-program.

This pilot study tested PBL as a pedagogical model of learning in the PBL-program and the participants and the tutors perceptions of this model and program will be presented in a forthcoming study. However, in the questionnaire about the quality of the PBL-program the participants described both positive and negative aspects. PBL was a pedagogical model which suited some participants very well but not all. It is probably difficult to create a patient education program that will fit all participants. Instead we should strive to create and offer the patients several different patient education programs. The most effective patient education must be presented to the right patient, at the right time and in the most appropriate way [21].

There were no statistical differences between the experimental group compared with the control group on HRQL, self-care ability, SOC, pain, quality of sleep or fatigue six month after the PBL-program. This can be due to that the PBL-program does not have this effect or that it takes longer time than six months to gain a change. It could also be due to the small study size. There is also a problem in the use of SF-36 that floor and roof effects can reduce the possible change over time in the extreme ends of the scales. Another limitation in this study was that there were few reliability and validity tested measuring instruments which
measures health promoting factors. The question is whether it is possible to measure the determinants with a measuring instrument which is designed to measure risk factors.

4.2. Conclusion
This pilot study has shown that with relatively little resources and time could a self-care promoting PBL-program enables people with rheumatic diseases who have had the disease for more than a year and had chronic musculoskeletal pain, sleep disturbances and/or fatigue for at least three months, to improve their empowerment. The participants also stated that they had implemented lifestyle changes which they had not done without the PBL-program.

4.3. Practice Implications
The results show that it is important to continue to develop PBL in patient education in order to find the very best way to use this pedagogical model in rheumatology care. There is also a need to improve and develop measuring instruments which could assess the outcomes from self-care promoting patient education.

Conflicts of interest
There existed no conflict of interest that would prejudice the impartiality.

Acknowledgments
The authors would like to thank the individuals who participated in this study and the Swedish Rheumatism Association, the Halland County Council, the South Regional Health Care Committee, the Stig Thunes Foundation Fund for Health Care Research, the Norrbacka-Eugenia Foundation, the Association of Rheumatology Nurses in Sweden and the Speshult Hospital for Rheumatic Diseases for financial support.
References


The one-year intervention

Inclusion questionnaire: 800 individuals

Pre-test: 202 participants

Experimental group: 54 participants

Experimental group: 51 participants began in the one year PBL-program in spring 2009

Dropout: 3 participants

Experimental group: 38 participants completed the one-year PBL-program in spring 2010 and answered the one-week post-test

Control group: 148 participants

Control group: 131 participants answered the one-week post-test in spring 2010

Dropout: 17 participants

Experimental group: 38 participants answered the six month post-test

Dropout: 0 participants

Control group: 124 participants answered the six month post-test

Dropout: 7 participants

Did not meet the inclusion criteria: 598 individuals

Study IV

Figure 1 Flow chart of the individuals in the intervention pilot study
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Experimental group</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test n=38</td>
<td>Pre-test n=124</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Sex</td>
<td>11 (29 %)</td>
<td>33 (27 %)</td>
</tr>
<tr>
<td></td>
<td>27 (71 %)</td>
<td>91 (73 %)</td>
</tr>
<tr>
<td>Age</td>
<td>56.4 (7.2)</td>
<td>55.2 (13.2)</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>(37-68 years)</td>
<td>(21-78 years)</td>
</tr>
<tr>
<td>Civil status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>8 (21 %)</td>
<td>22 (18 %)</td>
</tr>
<tr>
<td>Living with somebody</td>
<td>30 (79 %)</td>
<td>102 (82 %)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grade school</td>
<td>9 (24 %)</td>
<td>29 (24 %)</td>
</tr>
<tr>
<td>Junior secondary school/Vocational</td>
<td>9 (24 %)</td>
<td>24 (19 %)</td>
</tr>
<tr>
<td>school</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary school</td>
<td>12 (31 %)</td>
<td>40 (32 %)</td>
</tr>
<tr>
<td>College/university</td>
<td>8 (21 %)</td>
<td>31 (25 %)</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>11 (29 %)</td>
<td>61 (49 %)</td>
</tr>
<tr>
<td>Rural</td>
<td>27 (71 %)</td>
<td>63 (51 %)</td>
</tr>
<tr>
<td>Socioeconomic status, main occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group A</td>
<td>20 (53 %)</td>
<td>60 (48 %)</td>
</tr>
<tr>
<td>Group B</td>
<td>4 (10 %)</td>
<td>18 (15 %)</td>
</tr>
<tr>
<td>Group C</td>
<td>8 (21 %)</td>
<td>36 (29 %)</td>
</tr>
<tr>
<td>Group D</td>
<td>6 (16 %)</td>
<td>10 (8 %)</td>
</tr>
<tr>
<td>Socioeconomic status, current occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group A</td>
<td>10 (26 %)</td>
<td>35 (28 %)</td>
</tr>
<tr>
<td>Group B</td>
<td>5 (13 %)</td>
<td>16 (13 %)</td>
</tr>
<tr>
<td>Group C</td>
<td>6 (16 %)</td>
<td>16 (13 %)</td>
</tr>
<tr>
<td>Group D</td>
<td>17 (45 %)</td>
<td>57 (46 %)</td>
</tr>
<tr>
<td>Rheumatic disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local/general pain</td>
<td>1 (3 %)</td>
<td>6 (5 %)</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>1 (3 %)</td>
<td>6 (5 %)</td>
</tr>
<tr>
<td>Systemic rheumatic disease</td>
<td>5 (13 %)</td>
<td>23 (18 %)</td>
</tr>
<tr>
<td>Inf. joint disease</td>
<td>31 (81 %)</td>
<td>89 (72 %)</td>
</tr>
</tbody>
</table>

Group A: Manual workers
Group B: Assistant no manual employees
Group C: Intermediate/higher employees and upper-level executives
Group D: Others
Table 2 Differences between the experimental group and the control group at the pre-test, the one-week post-test and the six month post-test.

<table>
<thead>
<tr>
<th></th>
<th>Pre-test</th>
<th>One-week post-test</th>
<th>Six month post-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>E. group</td>
<td>C. group</td>
<td>E. group</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>n=162</td>
<td></td>
<td></td>
<td>p</td>
</tr>
<tr>
<td>PF</td>
<td>55.7 (23.5)</td>
<td>59.2 (23.2)</td>
<td>-3.5 (-12.1-5.0)</td>
</tr>
<tr>
<td>RP</td>
<td>45.4 (40.6)</td>
<td>43.6 (41.7)</td>
<td>1.8 (-13.3-17.0)</td>
</tr>
<tr>
<td>BP</td>
<td>41.7 (18.0)</td>
<td>44.0 (20.9)</td>
<td>-2.3 (-9.7-5.1)</td>
</tr>
<tr>
<td>GH</td>
<td>48.2 (21.5)</td>
<td>44.3 (21.8)</td>
<td>3.9 (-4.0-11.9)</td>
</tr>
<tr>
<td>VT</td>
<td>40.5 (19.9)</td>
<td>41.2 (24.8)</td>
<td>-0.7 (-9.4-8.0)</td>
</tr>
<tr>
<td>SF</td>
<td>65.5 (26.2)</td>
<td>69.1 (27.8)</td>
<td>-3.6 (-13.8-6.4)</td>
</tr>
<tr>
<td>RE</td>
<td>64.0 (38.3)</td>
<td>61.3 (42.4)</td>
<td>2.7 (-12.4-17.9)</td>
</tr>
<tr>
<td>MH</td>
<td>70.3 (18.7)</td>
<td>69.8 (22.5)</td>
<td>0.5 (-7.4-8.4)</td>
</tr>
<tr>
<td>SWE-RES-23, subscale 1</td>
<td>3.8 (0.7)</td>
<td>3.7 (0.7)</td>
<td>0.1 (-0.1-0.4)</td>
</tr>
<tr>
<td>SWE-RES-23, subscale 2</td>
<td>3.5 (0.8)</td>
<td>3.5 (0.7)</td>
<td>0.0 (-0.2-0.3)</td>
</tr>
<tr>
<td>SWE-RES-23, subscale 3</td>
<td>3.4 (0.7)</td>
<td>3.2 (0.8)</td>
<td>0.2 (-0.1-0.5)</td>
</tr>
<tr>
<td>SWE-RES-23, subscale 4</td>
<td>3.7 (0.6)</td>
<td>3.6 (0.6)</td>
<td>0.1 (-0.2-0.3)</td>
</tr>
<tr>
<td>SWE-RES-23, subscale 5</td>
<td>3.6 (1.0)</td>
<td>3.6 (1.1)</td>
<td>0.0 (-0.4-0.4)</td>
</tr>
<tr>
<td>SWE-RES-23, total score</td>
<td>3.6 (0.6)</td>
<td>3.5 (0.6)</td>
<td>0.1 (-0.1-0.3)</td>
</tr>
<tr>
<td>ASA-A</td>
<td>85.7 (11.7)</td>
<td>86.8 (10.2)</td>
<td>-1.1 (-4.9-2.8)</td>
</tr>
<tr>
<td>SOC</td>
<td>65.9 (11.7)</td>
<td>64.4 (12.8)</td>
<td>1.5 (-3.1-6.1)</td>
</tr>
</tbody>
</table>

Independent t-test for comparison between groups
* p<0.05 were considered as statistical significant difference
E.=Experimental
C.=Control
School of Health Sciences Dissertation Series


